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A Report of Survey Findings:  
**Diversity, Equity, and Inclusion Efforts**  
in Rare Disease Organizations

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## Acknowledgments

We would like to acknowledge each of the RDDC Patient and Caregiver Workgroup members who were an integral part of this work.

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# A Report of Survey Findings: Diversity, Equity, and Inclusion Efforts in Rare Disease Organizations

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*“You know, the biggest problem is access, and that’s access on many different levels. It’s a fact that people from other populations where, if you’re not a straight white male, the world looks different for you, right? It looks different for me. It looks different for my son. It looks different for every member of my family. I think that the rare disease community needs to do a better job reaching communities that don’t even realize that they’re affected by rare disease, can’t get in touch with the doctor, or are dismissed because they’re, you know, a woman of color for example. I mean honestly the most horrific stories I’ve heard in the rare disease space have come from women of color. It should not take 15 years of being dismissed by one doctor after another for you to get a diagnosis, and that’s the average of what it takes to diagnose a rare disease. If you’re a straight white man, it’s not taking 15 years.” – INTERVIEW PARTICIPANT*

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## About Survey Sponsors

### About Black Women’s Health Imperative (BWHI) Rare Disease Diversity Coalition (RDDC)



The Black Women’s Health Imperative (BWHI) is a national non-profit organization dedicated to advancing health equity and social justice for Black women, across the lifespan, through policy, advocacy, education, research, and leadership development. The organization identifies the most pressing health issues that affect the nation’s 22 million Black women and girls and invests in the best of the best strategies and organizations that accomplish its goals. You can find more information about BWHI at <https://bwhi.org>.



The Rare Disease Diversity Coalition (RDDC) is an initiative launched by BWHI to address the extraordinary challenges faced by historically under represented populations with rare disease. The RDDC brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to reduce racial disparities in the rare disease community. You can find more information about RDDC at <https://www.rarediseasediversity.org>.

### About Upequity



Upequity is a non-profit research and pilot lab focused on advancing systems and policy changes to create equal access to quality, affordable healthcare for those with rare or serious health conditions. Our success is defined through our work to advance system and policy changes, eliminate barriers, and produce tangible improvements in people’s lives. We achieve this through our research activities and our lab where we pilot new and innovative strategies that may benefit rare communities. Our Principal Investigators are talented researchers from diverse communities with direct experience in rare disease, health disparity research and direct patient and caregiver research. You can find more information about Upequity at <https://www.upequity.org>.



# Executive Summary

## Project Overview

The project's purpose was to look at the current state of diversity, equity, and inclusion (DEI) practices and initiatives of patient advocacy organizations, and to identify gaps and develop recommendations related to outreach, education, and support among rare disease patients of color. This assessment included a survey directed at patient advocacy organizations and qualitative interviews of a limited number of key organizational leaders. For this report, the survey and key informant interview results have been analyzed to inform the development of best practices and recommendations to improve outreach and communication to rare disease diverse populations.

We opened our survey for data collection from June 13, 2022 to September 2, 2022. We received 127 individual responses to our survey representing at least 38 unique organizations (identifying one's organization by name was optional) in addition to conducting in-depth informational interviews and focus groups with several organizations to provide more qualitative insights into factors that affect DEI in the rare disease space.

The survey and qualitative interviews focused on the following areas:

- Diversity in rare disease organizations
- Current organizational efforts to address diversity, equity, and inclusion
- Suggestions for improving diversity, equity, and inclusion efforts within rare disease organizations



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*“DEI is a part of our framework. It is a part of our strategic plan...But I know that internally we’re trying to do more. We’re trying to make sure DEI is fully ingrained in everything that we do, everything that we take on, and requiring different trainings within the entire staff to make sure that that’s reflected with everyone within the organization too, so that it’s outward facing as well.” – INTERVIEW PARTICIPANT*

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Data from the survey and key informant interviews indicated a lack of knowledge of how to incorporate DEI concepts effectively and efficiently throughout an organization’s framework due to various organizational specific needs. Moreover, respondents identified DEI as an add-on to programs rather than intrinsic to the fabric of their organization. Therefore, we identified the following key findings and high-level recommendations.

## Key Findings

1. Current DEI initiatives centered on offering educational materials in accessible formats (i.e., reading levels, different languages), attending diversity workshops, and engaging community groups to reach diverse groups.
2. There was no significant difference in initiatives/activities based on organization size. Organizations that identified as having 2-9 employees/volunteers indicated increased efforts compared to other organizations.
3. Overall, survey respondents and key informant interview participants indicate they are not satisfied with their current progress but are actively initiating changes.
4. Overall organizational commitment to and accountability for DEI is based on employee title. Most respondents indicated several accountability initiatives within their organizational structure.
5. Most organizations are creating DEI targeted educational materials and adding DEI efforts to their websites because of its broad reach and relative cost effectiveness.
6. Organizations are actively promoting trials to diverse populations by offering accessible educational materials and engaging community groups to reach diverse groups.
7. The most popular strategy for measuring the respondent’s organization’s DEI effectiveness is collecting appropriate demographic information from their employees/volunteers.
8. Respondents clearly expressed the need to collect demographic information and many organizations are making efforts to collect demographic information, which is typically done on an *ad hoc* basis. However, survey respondents expressed a need to understand how this information could strategically be used to inform larger DEI efforts.
9. Overarching results indicated that organization respondents who participated in the survey communicate their DEI efforts in numerous diverse ways.
10. Lack of staff bandwidth and expertise were frequently cited as deterrents to more robust DEI strategies.

## High-Level Recommendations

1. Create DEI goals and objectives within the organization's strategic plan or framework.
2. Provide guidance on how to develop organization-wide outcome measures that are relevant to organizational mission and measurable to monitor the effectiveness of DEI-focused initiatives.
3. Engage in targeted recruitment efforts of underserved/minority populations at the beginning of projects that drive inclusion practices throughout organizations.
4. Create DEI resources that offers guidance to ensure that websites, social media, and other informational material reflect all areas of DEI (i.e., imagery, font size, wording).
5. Create simple strategies to collect demographic information that can be streamlined across the organization (i.e., questions within current registries or natural history studies).
6. Create accessible DEI toolkits that organizations can use to measure their effectiveness (i.e., simple surveys, questionnaires, instructional guides on evaluation).
7. Provide information about clinical trials and research overall through all communication channels for reach/accessibility to engage diverse participants for clinical trial participation.
8. Offer specific training opportunities on how to sensitively and thoroughly collect demographic information, as well as training on how to utilize this data to inform initiatives centered on improving DEI.





## Introduction

Disease diagnosis among rare disease patients can take seven years on average<sup>1</sup>. In addition to the prolonged disease diagnostic odyssey, diversity in the rare disease research field is of great public health concern<sup>2</sup>. An estimated 25-30 million Americans have a rare disease, equating to more than 10,000 different rare diseases<sup>3</sup>. There is a higher incidence and prevalence of some rare disease among ethnic and racial minority groups compared to the general population<sup>4</sup>. These disparities exist for various reasons including environmental, linguistic, cultural, genetic, limited access to care, and socioeconomic factors<sup>4</sup>. Moreover, the demographics of the US population are shifting with nonwhites representing more than 50% of the population by 2045<sup>5</sup>. As this shift in demographics occurs, there is an increased need to create more diverse strategies that engage a diverse population.

## Purpose

The project aimed to conduct an audit and analysis of the current state of rare disease patient organizations—with a focus on providing best practices and recommendations related to outreach, education, and support of patients of color with rare disease. This assessment included a survey directed to patient advocacy organizations and qualitative interviews of a limited number of key organizational leaders. For this report, the survey and key informant interview results have been analyzed to inform the development of best practice tools, education, and resources to improve outreach and communication to rare disease diverse populations. This survey focused on the following:

- Diversity in rare disease organizations
- Current organizational efforts to address diversity, equity, and inclusion
- Suggestions for improving diversity, equity, and inclusion efforts within rare disease organizations



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*“Inclusion, I guess, for me is making sure that different people are represented and have a chance to have a seat at the table. I guess, and being able to have an input of different perspectives and viewpoints, and backgrounds and all the different parts of one’s identity.”* – INTERVIEW PARTICIPANT

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## Methods

### Survey Development/Administration

We conducted an online survey titled *Diversity, Equality, and Inclusion Efforts in Rare Disease Organizations Survey*. This DEI survey was developed to address rare disease patient organizations’ efforts related to outreach, education, and support of patients of color with rare disease. The purpose was to explore the participants’ opinions on DEI in the rare disease community, current organizational efforts to address DEI, suggestions for improving DEI efforts within the organization, and to identify best practices and recommendations for use for the larger rare disease community.

The survey questions, which were mainly close ended, addressed individual respondents’ demographics, respondent organization demographics, organization communication methods, DEI effectiveness, DEI activities, inclusion services, clinical trial awareness efforts, commitment to DEI, accountability to DEI, and interest to participate in a follow-up individual interview. The survey questions were written in consultation with the RDDC Patient and Caregiver Workgroup and piloted with different stakeholders to ensure the questions were relative, accessible, and comprehensible.

The Qualtrics platform was used to create, publish, and distribute the survey. We opened our survey for data collection from June 13, 2022 to September 2, 2022. The survey was offered in English and was disseminated mainly through social media, patient organizations, and RDDC. Our initial goal was 100 participants completing the survey.

We received 127 total survey responses. Nineteen left their contact information so they could participate in a follow-up interview. An additional 44 participants named their organizations. We submitted and obtained an Institutional Review Board (IRB) exemption for this project.

### Individual Interviews

In-depth individual interviews were conducted with employees or volunteers representing several different patient advocacy organizations. Nineteen individuals voluntarily submitted their contact information within the survey for follow-up. We followed up with all 19 prospective respondents to confirm participation, and we received responses with a confirmed interview date/time from five individuals. The goal of these individual interviews was to provide more qualitative insights into factors that affect DEI in the rare disease space. The guide was semi-structured, and questions focused on further understanding concerns, if any, among rare disease organizations. If concerns were identified, participants were probed to identify potential strategies that could assist in creating a more diverse, equitable, and inclusive rare disease space. All interviews and focus groups were transcribed and recorded if consent was provided. Findings were used to help inform the best practices and recommendations included in this final report.

Sample questions included: What do diversity and equity in rare disease mean to you? How would you describe the diversity among employees in your organization? How does DEI fit within your organization’s framework? Do you think your organization could further improve diversity, equity, and inclusion in your workplace? What are some possible solutions to increase rare disease patients’ or caregivers’ involvement with patient advocacy groups?

# Overview of Survey Respondents

We received 127 individual responses to the survey. Respondents were asked to voluntarily identify the organization they work for within the survey. As a result, we were able to identify 38 unique organizations by name, with 83 individuals responding anonymously.

Most respondents who completed the survey were 35-44 years old; were female (87.9%); and indicated their highest education as receiving a master’s, professional, or doctorate degree (50%). The majority of respondents were White, followed by Black, African American, or African (67.7%, 15.4% respectively).

**Figure 1. Survey Respondent Characteristics**

Gender	Number	Percent
Male	6	9.1
Female	58	87.9
Gender variant/Non-confirming	1	1.5
Age	Number	Percent
18-24 years	2	3.0
25-34 years	13	19.7
35-44 years	22	33.3
45-54 years	16	24.2
55-64 years	9	13.6
65-74 years	2	3.0
75 years or above	1	1.5
Education Level	Number	Percent
Some college	3	4.6
Associate’s degree or technical school	2	3.0
Bachelor’s degree	27	40.9
Master’s, Professional, or Doctorate degree	33	50.0
Race/Ethnicity	Number	Percent
American Indian or Alaska Native	2	3.0
Asian	4	6.2
Black, African American, or African	10	15.4
Hispanic, Latino, or Spanish	7	10.8
Middle Eastern or North African	2	3.1
Native Hawaiian or Other Pacific Islander	1	1.5
White	44	67.7
Afro-Caribbean	1	1.5
None of these fully describe me (Please specify.)*	2	3.1

*\*Note: Two participants responded to this question. One participant responded as Indigenous. The other participant responded as Greek American.*

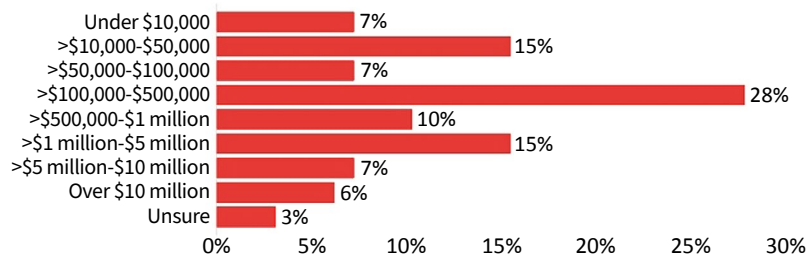
In terms of organizations represented in the survey, most had an annual revenue of >\$100,000 - \$500,000 (27.8%) followed by >\$10,000 - \$50,000 (15.5%) and >\$1 million - \$5 million (15%) (Figure 2). Most organizations have between 2–9 employees (43.1%) followed by all volunteer organizations (15.7%). Most respondents worked more than 35 hours a week (69.4%) and indicated they were President or CEO (33.3%), followed by Director (16.7%). Many respondents (11%) indicated the “other” category and listed the following as their role: health equity program specialist, outreach liaison and/or medical advocate, family support, fellow, patient advocate, executive director, coordinator, and communications coordinator.

Most respondents identified their organizations as headquartered in the South, followed by the Northeast, West, and Midwest (48%, 19%, 15%, 10% respectively). Additional respondents indicated “other” or that their organization was not officially headquartered in any state, with volunteers operating in a virtual capacity (2%, 8% respectively).

**Figure 2. Organization Annual Revenue**

What is the organization’s annual revenue?

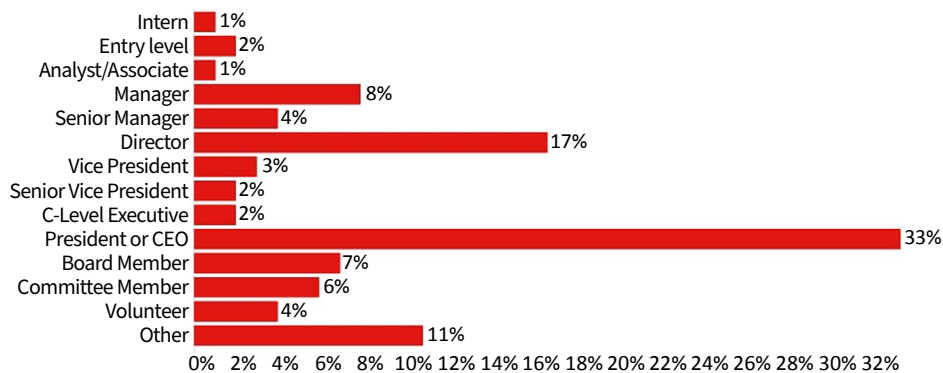
97 Responses



**Figure 3. Respondent Title at the Organization**

What is your current title at the organization?

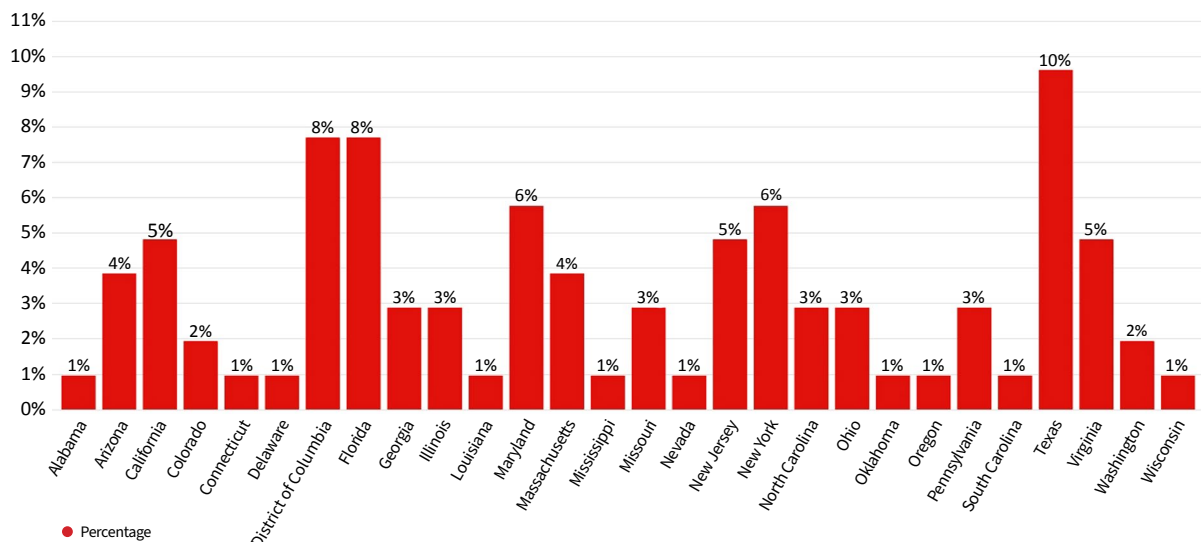
102 Responses



**Figure 4. Organization Location**

The following questions are about the organization you are employed/volunteer at. Where is the organization headquartered?

104 Responses



# Key Findings

**Current initiatives centered on offering educational materials in accessible formats (i.e., reading levels, different languages) and attending diversity workshops.**

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1. There was no significant difference in initiatives/activities based on organization size. Organizations that identified as having 2-9 employees/volunteers indicated increased efforts compared to other organizations.
2. Organizations are actively promoting trials to diverse populations.
3. Additionally, organizations are engaging community groups to reach diverse groups.
4. Respondents clearly expressed the need to collect demographic information; however, they expressed a need to understand how this information could strategically be used to inform more considerable DEI efforts.
5. The most popular strategy for measuring the respondent's organization's DEI effectiveness was collecting appropriate demographic information from their employees/volunteers.
6. Survey respondents and key informant interview participants indicated they were not satisfied with their current progress but are actively initiating changes.
7. Overarching results indicated that organization respondents who participated in the survey communicate their DEI efforts in numerous ways.
8. Higher-level employees were less favorable of their organization's commitment to and accountability for DEI key findings.
9. There was not a significant difference in overall organizational commitment to and accountability for DEI based on employee title. Most respondents indicated several accountability initiatives within their organizational structure.
10. Most organizations are creating DEI targeted educational materials and adding DEI efforts to their websites because of its broad reach and relative cost effectiveness.
11. Many organizations are making efforts to collect demographic information, which is typically done on an *ad hoc* basis, and it was often unclear to survey respondents how this information would be used to help inform larger DEI efforts.
12. Organizations are actively promoting clinical trials to diverse populations by offering accessible educational materials and engaging community groups to reach diverse groups.
13. Lack of staff bandwidth and expertise were frequently cited as deterrents to more robust DEI strategies.

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*“If you know better you do better, and especially working in this space, I think that everybody wants to be helpful, and wants to be inclusive and don't want to say things that alienate certain individuals, and even being able to bring different types of experiences and knowledge to the conversation. A part of that is having that kind of mindset going into it. It's easy to if you're not being intentional about diversity, equity, inclusion to kind of miss that step so the more that we can have the trainings, have the conversations, and speak with people who are different from us, I think, we will continue to do more, and do better to support all our different stakeholders.” – INTERVIEW PARTICIPANT*

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*“I feel like there are large gaps that we are missing in the community, and I feel like they are the most underserved populations. They are the most overlooked populations and I don’t know how you tap into those populations without doing like grassroots efforts. I don’t know what that looks like but I would love to be a part of creating what that looks like, if that makes any sense.” – INTERVIEW PARTICIPANT*

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## Detailed Findings



### 1. Organizational Commitment to and Accountability for DEI<sup>1</sup>

#### Overall Organizational Commitment to and Accountability for DEI Key Findings:

- Higher-level employees were less favorable of their organization’s commitment to and accountability for DEI key findings.
- There was not a significant difference in overall organizational commitment to and accountability for DEI based on employee title. Most respondents indicated several accountability initiatives within their organizational structure.

#### Overall Organizational Commitment to and Accountability for DEI Recommendations:

- Create and hire for a position specifically related to DEI.
- Create DEI specific accountability metrics across organization activities to guide efforts.
- Create a DEI mission and vision for the organization.
- Create a DEI webpage that assesses the organization’s DEI efforts throughout the year.

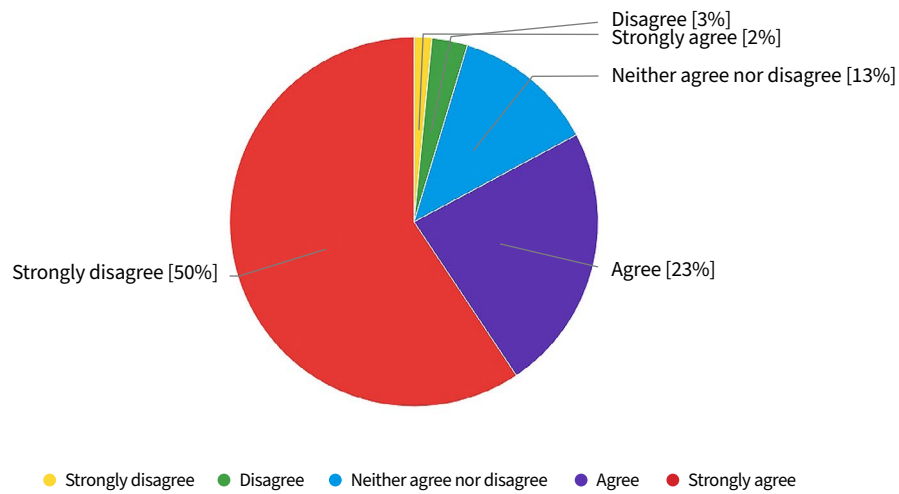
Survey respondents were asked about their coworkers’/volunteers’ commitment to creating an inclusive environment. Most respondents indicated they strongly agreed there was a commitment to creating an inclusive environment (59%), while a small proportion disagreed or strongly disagreed to this statement (3%, 2% respectively). In addition, respondents were specifically asked about their leadership’s commitment to an inclusive environment. Similar to responses related to coworkers/volunteers, respondents indicated they strongly agreed (50%) with this statement with a relatively small proportion of respondents indicating they disagreed or strongly disagreed (2%, 2% respectively).

<sup>1</sup> We based our understanding of patient advocacy organizations’ commitment to DEI on the following survey questions: “Employees/volunteers at the organization demonstrate a commitment to creating an inclusive environment.” (#23), and “Leadership at the organization demonstrates a commitment to creating an inclusive environment.” (#24). We based our understanding of patient advocacy organizations’ accountability for DEI on the following survey questions: “The diversity, equity, and inclusion program leader is...” (#21), and “The following statement best describes accountability for diversity, equity, and inclusion within the organization.” (#24).

**Figure 5. Employees/Volunteers Commitment to Creating an Inclusive Environment**

Leadership at the organization demonstrates a commitment to creating and inclusive environment.

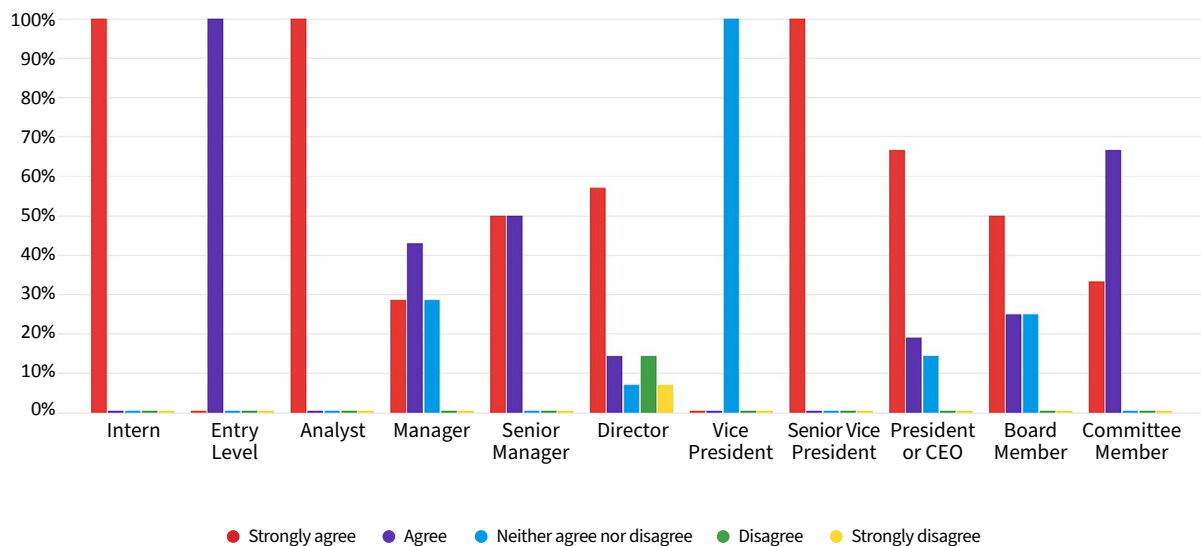
64 Responses



**Figure 6. Employees/Volunteers Commitment to Creating an Inclusive Environment Response by Employee/Volunteer Title**

Leadership at the organization demonstrates a commitment to creating an inclusive environment.

64 Responses




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*“To me personally, you know, diversity to me just basically represents our community as a whole. I think it’s important to represent men and women, people of color, whatever gender you identify with equally and provide the same services to all of those people, and you know the past few years have been difficult for me personally, for my family personally, because I feel like the concept of diversity, and the acceptance of diversity is just being spit on. I feel like as a patient advocacy organization that it’s our responsibility to provide services and represent every facet of people regardless of you know where they come from, what they look like, how they identify.” – INTERVIEW PARTICIPANT*

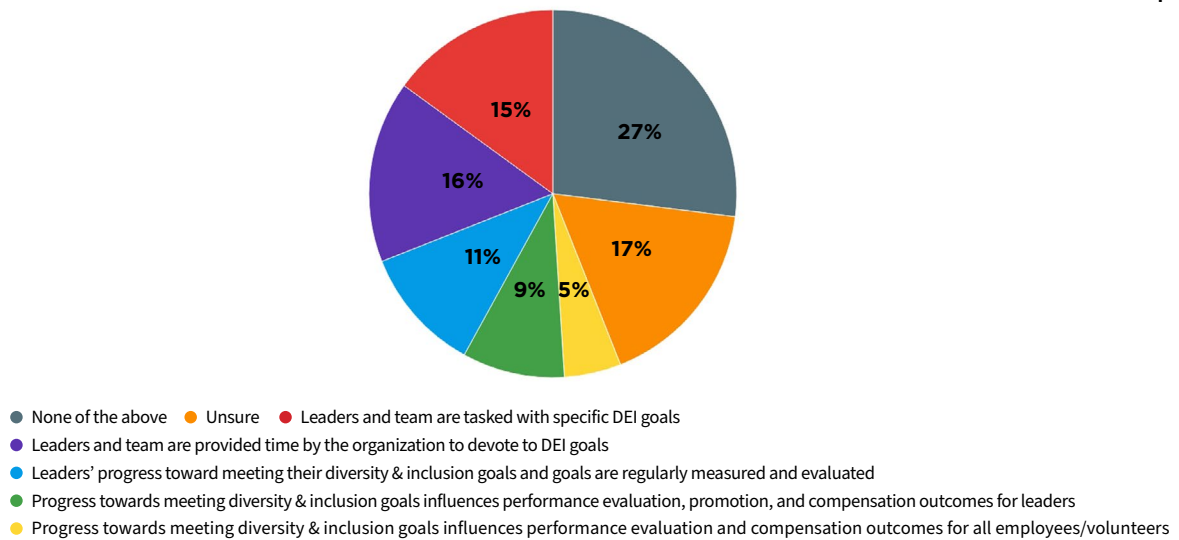
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When asked about their organization’s accountability for DEI, more than 40% indicated they were unsure or none of the above represented their organization’s accountability efforts (17%, 27% respectively). Others indicated the organization allowed leaders and teams time to devote their efforts to DEI goals (16%), while others indicated internal incentives towards meeting diversity and inclusion goals, such as performance evaluations and compensation outcomes (5%). In addition, respondents were asked to identify who the diversity, equity, and inclusion program leader was, if any, within the organization. Most respondents indicated no clear leader for diversity and inclusion efforts (51%), while others indicated a staff member as the individual within this role who also has a variety of other non-diversity related responsibilities and priorities assigned to them as well (19%).

**Figure 7. Organization DEI Accountability**

The following statement best describes accountability for diversity, equity & inclusion within the organization. (Select all that apply.)

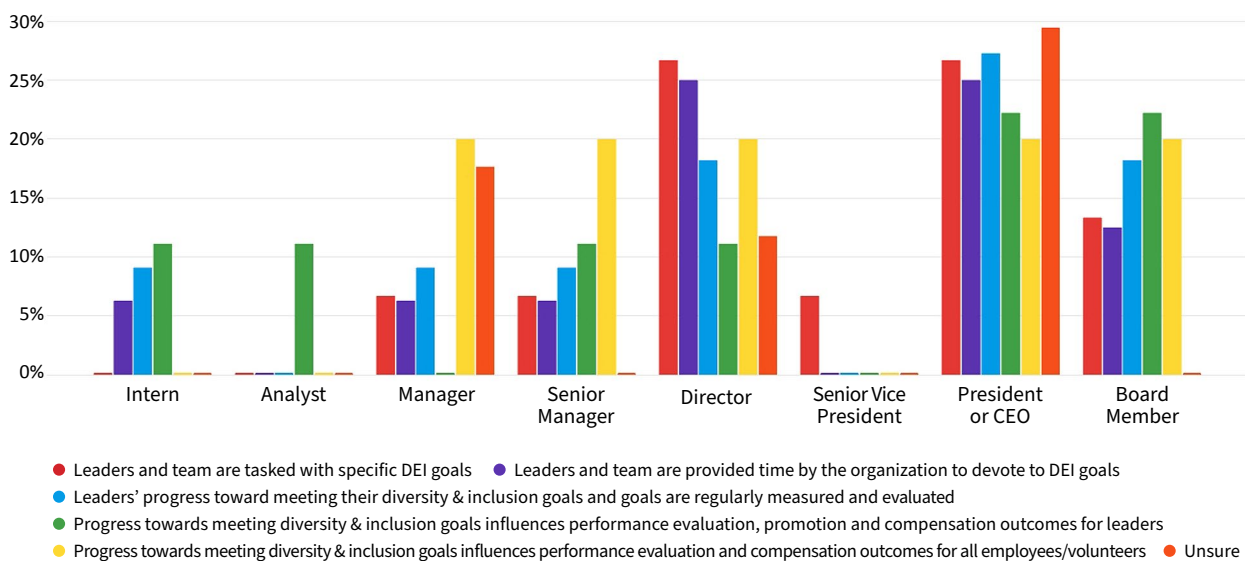
66 Responses



**Figure 8. Organization DEI Accountability Response by Employee/Volunteer Title**

The following statement best describes accountability for diversity, equity & inclusion with the organization. (Select all that apply.)

66 Responses





## 2. DEI Initiatives and Activities<sup>2</sup>

### DEI Initiatives and Activities Key Findings:

- Although a need was expressed, less than half of respondents currently have programs that address the recruitment of diverse candidates.
- Less than half of respondents identified current efforts geared towards providing targeted development opportunities for diverse employees/volunteers.
- Current methods to address diversity in volunteer/employee recruitment focused more on flexibility such as engaging volunteers on a fully remote basis and hiring employees on a fully remote basis.
- Current initiatives centered on offering educational materials in accessible formats (i.e., reading levels, different languages) and attending diversity workshops.
- There was no significant difference in initiatives/activities based on organization size.
- Organizations that identified as having 2-9 employees/volunteers indicated increased efforts compared to other organizations.

### DEI Initiatives/Activities Recommendations:

- Create resources that identify potential opportunities to engage diverse individuals in a creative manner.
- Conduct a needs assessment with staff to identify areas of interest for targeted development opportunities.
- Post job/volunteer opportunities in various spaces based on the target audience (HBCUs, Black Nurses Association, etc.).
- Identify free, reduced-cost, or paid DEI workshops for engaging staff.
- Create a DEI toolkit for accessible websites, social media, etc., for patient advocacy organizations.

Respondents were asked about their organization’s DEI activities that addressed a variety of programs. Less than half of respondents identified having programs to specifically address the recruitment of diverse candidates (41%). Others indicated their efforts to provide targeted development opportunities for diverse employees/volunteers (35%). Respondents who answered “other” mentioned posting information in targeted places to attract a more diverse pool of applicants for their staff.

<sup>2</sup> We based our understanding of patient advocacy organizations’ DEI activities by combining the following survey questions: “The organization has programs in place to” (#22) and “Over the past 12 months, which steps has the organization taken to achieve diversity in recruiting employees/volunteers?” (#11). We based our understanding of patient advocacy organizations’ initiatives by combining the following survey questions: “What inclusion measures has the organization introduced over the past 12 months?” (#12), and “Does the organization offer any of the following services?” (#17).

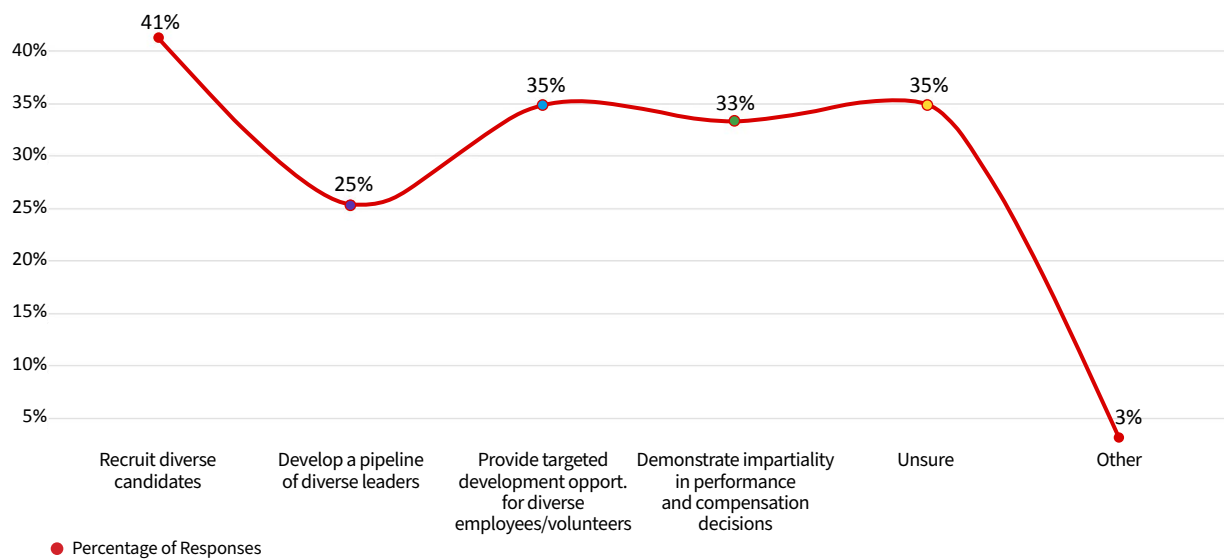


In addition, survey respondents were asked about their organization’s efforts over the past 12 months to achieve diversity in their volunteer/employee recruitment. Most respondents identified several intentional efforts such as engaging volunteers on a fully remote basis (62%), hiring employees on a fully remote basis (62%), hiring from diverse and varied geographic locations (46%), and ensuring job postings are worded to eliminate bias (36%). Still others identified efforts such as “making a conscious and public effort to recruit and include students with disabilities”, “working with a DEI consultant and starting an internal DEI committee”, and “customizing interview questions to more closely align with position responsibilities and to allow room for inclusion of experience over education. Also, conducting an organization-wide reflection activity to identify three specific areas to address equity over the next three years.”

**Figure 9. Organization Diversity Program Goals**

Thinking about the programs in place at the organization you are employed/volunteer at, select the answer that most closely applies... The organization has programs in place to (Select all that apply)

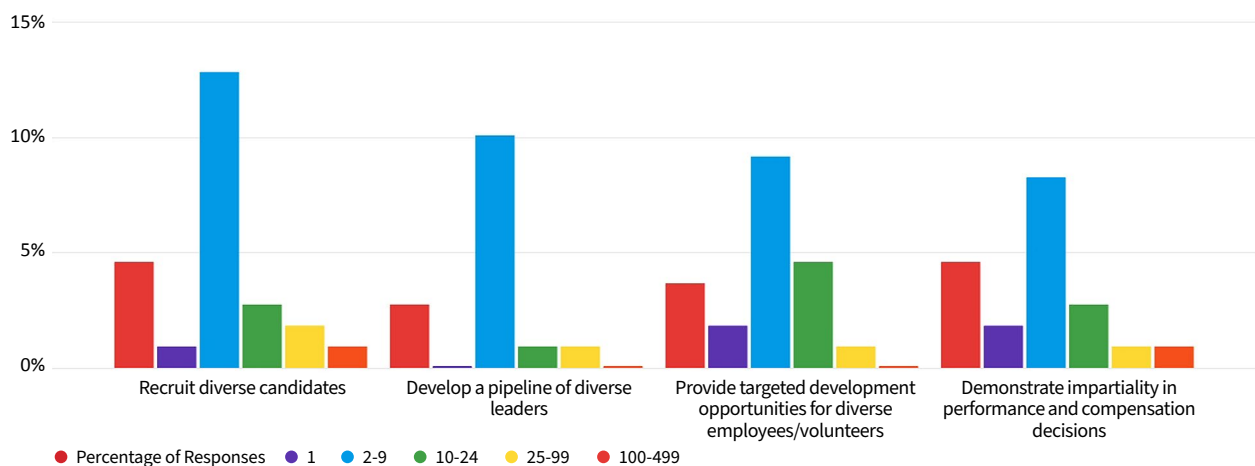
63 Responses



**Figure 10. Organization Diversity Program Goals Response by Number of Employees/Volunteers at the Organization**

Thinking about the programs in place at the organization you are employed/volunteer at, select the answer that most closely applies... The organization has programs in place to (Select all that apply.)

63 Responses



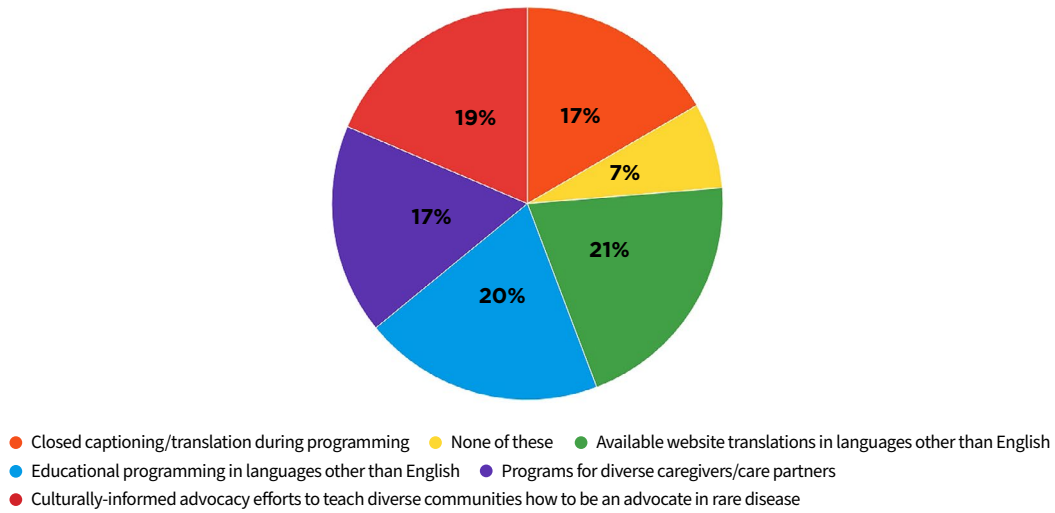
*“It’s just it hits at large. So it can affect everyone and anyone without bias so, I feel like we have a responsibility as a rare disease community to make sure that we are reaching everyone in the rare space.” – INTERVIEW PARTICIPANT*

Survey respondents were asked about inclusion measures implemented within the past 12 months. More than half of respondents indicated current efforts centered on offering educational materials at accessible reading levels, in different languages, etc. (55%), and attendance at diversity workshops (51%). Additional efforts included following community and diverse groups on social media (45%) and providing resources on how employees and/or volunteers can get involved (43%). Respondents were also asked to identify current inclusion services offered by the organization. Respondents indicated they utilize website translations in languages other than English (21%), and educational programming in languages other than English (20%), while 7% indicated offering none of the listed options.

**Figure 11. Organization DEI Services**

Does the organization offer any of the following services? (Select all that apply.)

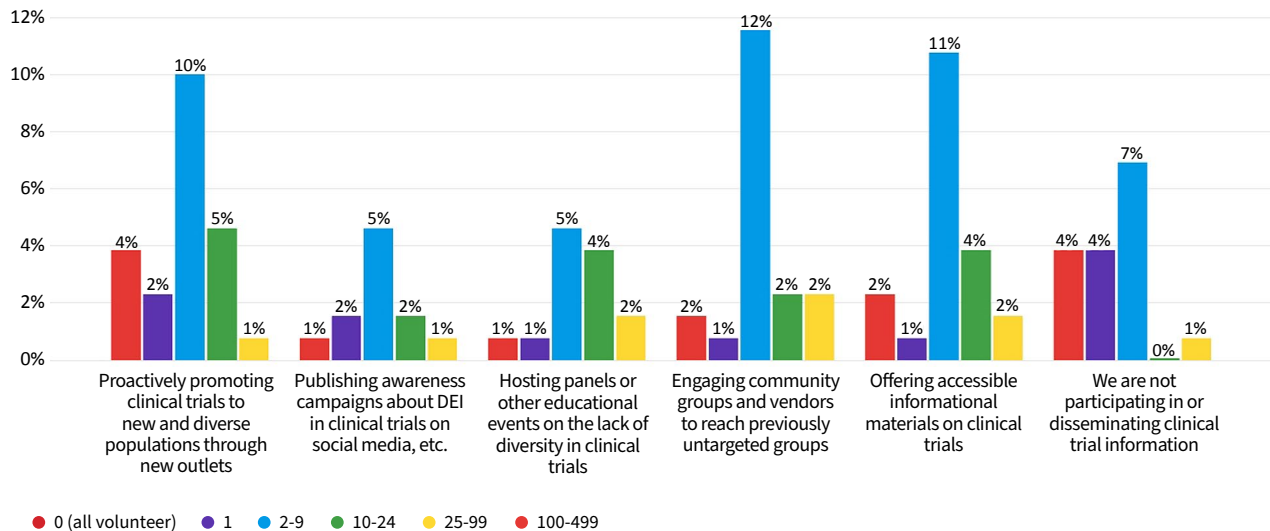
69 Responses



**Figure 12. Organization DEI Services Response by Organization Annual Revenue**

Does the organization deliberately engage in any of the following to ensure the participation of a diverse rare disease population in the clinical trial process? (Select all that apply.)

70 Responses





### 3. DEI Communication Strategies<sup>3</sup>

#### DEI Communication Strategies Key Findings

- Overarching results indicated that organization respondents who participated in the survey communicate their DEI efforts in numerous diverse ways.
- Most respondents indicated they were creating diverse informational materials and adding DEI efforts to their homepage.
- Key informant interviews reflected these results indicating that it's often easier to implement initiatives using current resources such as websites, etc., because they are cost efficient.
- Additionally, we determined that websites predominantly serve as communication methods for organizations that also reflect a commitment to sharing information that patient organizations feel can be shared more broadly across the rare disease community.
- There was not a significant difference in communication strategies based on organization size. Organizations who identified as having 2-9 employees/volunteers indicated increased efforts compared to other organizations.

#### DEI Communication Strategies Recommendations:

- Create DEI checklist that offers guidance to ensure that websites include social media, and other informational material reflect all areas of DEI (imagery, font size, wording, etc.).
- Connect with diverse organizations across social media platforms that may not be specific to your disease.

Survey respondents identified several efforts surrounding their DEI communications. More than half indicated the organization they worked for created diverse informational materials (i.e., photos, language, translation) for their rare disease stakeholders (51%). In addition, many identified the importance of adding their commitment to DEI on their websites or social media (32%). Respondents also identified additional methods of communication, such as securing an external consultant training in DEI, HR to review and provide recommendations for revisions to policies and procedures and discussing DEI topics in conversations with partners and stakeholders (14%, 20% respectively). We also had several respondents answer that their organization is making progress in communicating their DEI efforts.

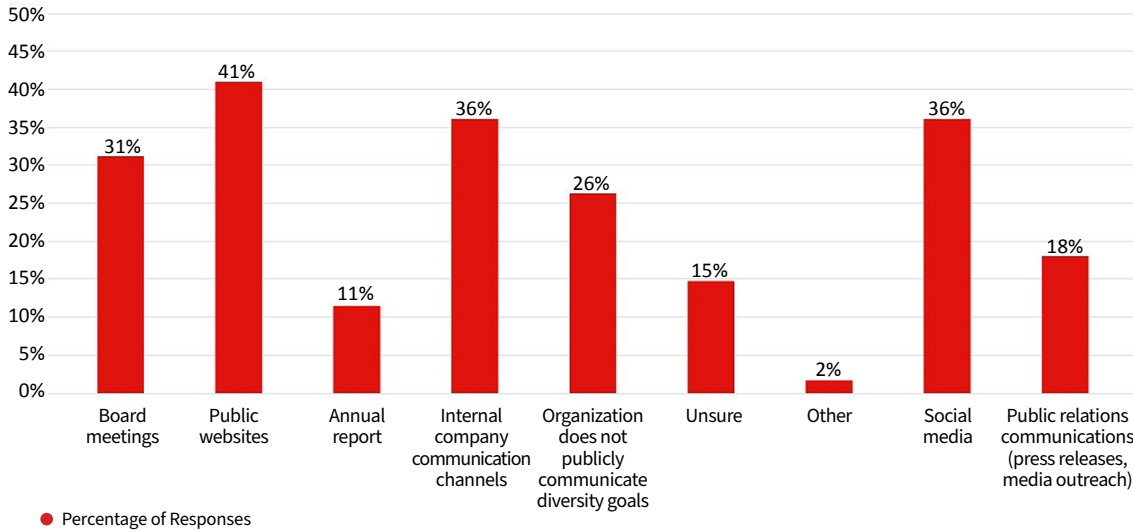
<sup>3</sup> We based our understanding of patient advocacy organizations' communication methods for DEI by combining the following survey questions: "How is the organization currently communicating their efforts around DEI?" (#13), "If the organization publicly communicates information about its diversity goals, where is the information published?" (#18), "Organization's leaders communicate about diversity." (#19).

In addition, to identify where the information is published, we asked respondents if the organization communicates their diversity goals. For the most part, respondents identified their websites, internal communications, and social media as the most prominent methods of communication (41%, 36%, 36% respectively). Lastly, we asked respondents how their leaders communicated their DEI efforts. More than 15% identified their organization’s leadership provided communication on diversity goals very infrequently or not at all.

**Figure 13. DEI Communication Strategies**

Thinking about the strategy and goals of the organization you are employed/volunteer at, select the answer that most closely applies... If the organization publicly communicates information about its diversity goals, where is the information published? (Select all that apply.)

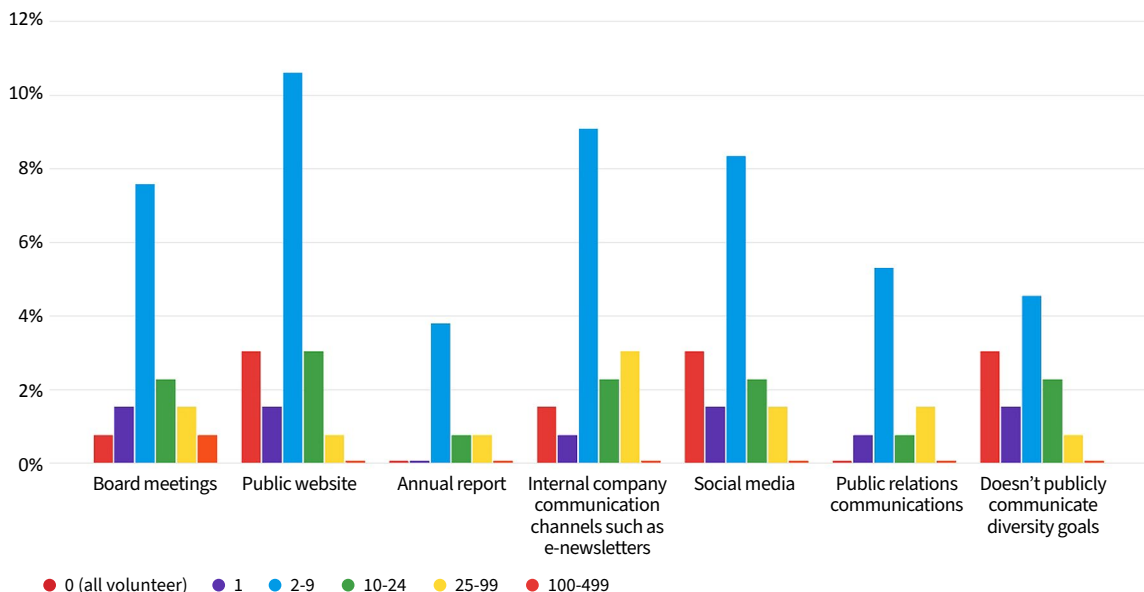
61 Responses



**Figure 14. DEI Communication Strategies Response by Number of Employees/Volunteer at the Organization**

Thinking about the strategy and goals of the organization you are employed/volunteer at, select the answer that most closely applies... If the organization publicly communicates information about its diversity goals, where is the information published? (Select all that apply.)

61 Responses







#### 4. Demographic Information Collection Efforts<sup>4</sup>

##### Demographic Information Collection Efforts Findings:

- Overarching results indicated that organizations are making efforts to collect demographic information.
- Demographic information is often collected randomly to serve specific purposes for a specific initiative but is not routinely conducted.
- Respondents clearly expressed the need to collect demographic information; however, they also expressed a need to understand how this information could strategically be used to inform more considerable DEI efforts.
- Many respondents expressed a lack of knowledge of data collection or the lack of staff to collect demographic information collection with their already overburdened small staff teams.
- Managers, directors, vice presidents, presidents, and board members were more likely to indicate no, or unsure about their demographic information collection.

##### Demographic Information Collection Efforts Recommendations:

- Create easy, accessible opportunities for individuals to leave their contact information when accessing resources on the website.
- Create a quick demographic survey template that can be used across the organization's efforts.
- Create a "How to Evaluation Guide" as a lay resource that organizations can use to implement evaluation strategies across organizations.
- Offer specific training opportunities on how to sensitively and thoroughly collect demographic information, as well as training on how to utilize this data to information initiatives centered on improving DEI.

Survey respondents were asked about their organization's efforts at collecting demographic information (race/ethnicity, geographical, location, education, etc.) for the served community. More than half (53%) of survey respondents indicated they collected this information. Others suggested they only collected geographic locations, residential information, demographic information for specific purposes but not largely, and/or information on a voluntary basis resulting in not many responses. Other organizations indicated they were starting to collect this information.

<sup>4</sup> We based our understanding of patient advocacy organizations' data collection of demographic information by combining the following survey questions: "Does the organization collect demographic information (race/ethnicity, geographical location, education, etc.) for the community (ies) it serves?" (#15), "Does the organization regularly review this demographic information (race/ethnicity, geographical location, education, etc.) and use it to inform efforts to improve the reach of its services/programs to new and diverse groups?" (#16).

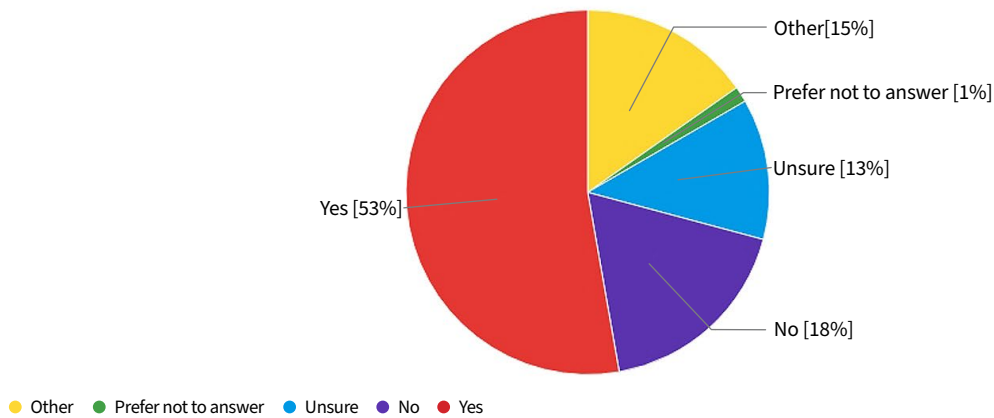
For respondents who originally indicated their organization collected demographic information, they were asked to specify whether this information was used to inform current or future efforts. Respondents indicated their organizations utilized this information for future programming (47%), but others mentioned this information was not being used to improve the organization’s reach (20%). For other respondents who answered “other”,

responses included, “We are working to hire more employees to help with this effort.”, “Race/ethnicity data collection began last year; plan to regularly analyze once we have a core data set.”, “Not yet but we are just building our database.”, “Yes we look at it, we aren’t always sure how to expand and improve.”, “We are a small staff of 1 who is part time, so while we’d be interested in doing this, we don’t currently have the capacity to review this information regularly.”

**Figure 15. Demographic Information Collection**

Does the organization collect demographic information (race/ethnicity, geographical location, education, etc.) for the community (ies) it serves?

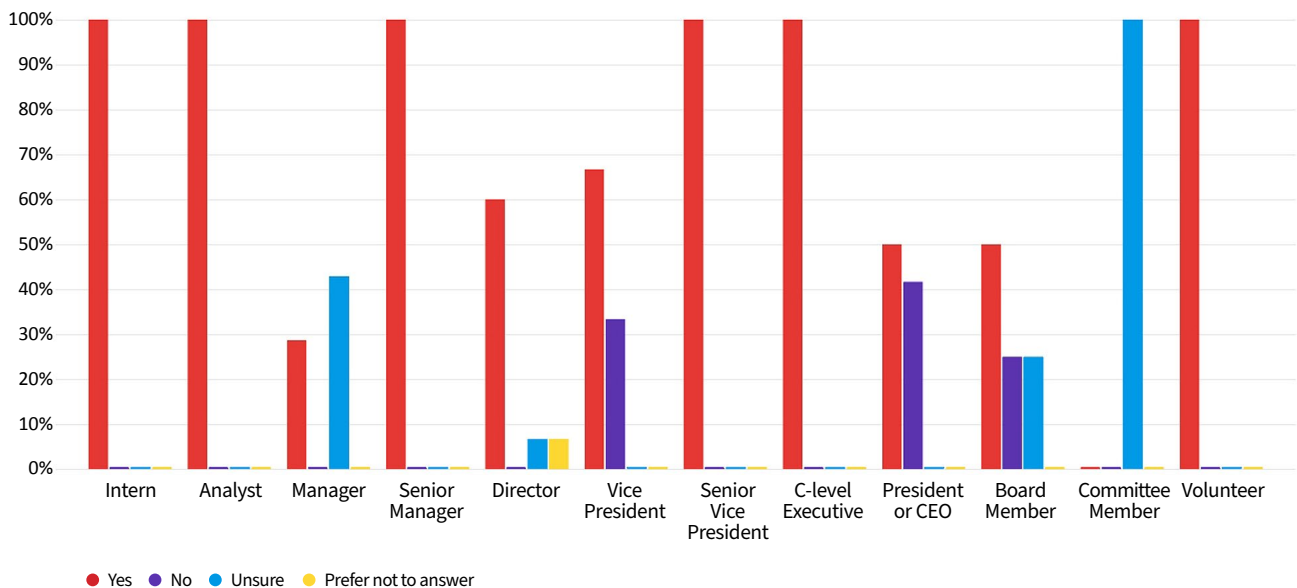
72 Responses



**Figure 16. Demographic Information Collection Response by Employee/Volunteer Title**

Does the organization collect demographic information (race/ethnicity, geographical location, education, etc.) for the community (ies) it serves?

72 Responses



*“You feel like you know, you get the response that you’re typically used to getting when it comes to clinical research. We conduct our outreach mainly from the list serve we have from our email list. So we don’t get much push back, but we also don’t get as diverse of a population because the groups included in our list are already not very diverse. However we’ve also been doing some social media outreach for these events.” – INTERVIEW PARTICIPANT*



## 5. Pursuing Diversity in Clinical Trials<sup>5</sup>

### Pursuing Diversity in Clinical Trials Key Findings:

- Organizations are actively promoting trials to diverse populations.
- Many respondents indicated an effort by their organization to continue offering accessible trial informational materials.
- Additionally, organizations are engaging community groups to reach diverse groups.
- There was no significant difference in pursuing diversity in clinical trials based on organization size. Organizations that identified as having 2-9 employees/volunteers indicated increased efforts compared to other organizations.

### Pursuing Diversity in Clinical Trials Recommendations:

- Post clinical trial information on patient advocacy organization’s websites, social media, and other public-facing communication methods.
- Create a lay guide that provides an overview of a clinical trial and how to participate.
- Provide opportunities for the public to participate in forums that serve as an educational tool for families living with rare disease to address clinical trial information.
- Provide information about clinical trials through all modes of communication, even those outside of social media.
- Engage in targeted recruitment efforts of underserved/minority populations.

In the area of clinical trials, respondents identified whether their organization engaged in activities to ensure diverse participation in the clinical trial process. Most respondents identified proactively promoting clinical trials to new and diverse populations through new outlets (40%), offering accessible informational materials on clinical trials (36%), and engaging community groups and vendors to reach non-targeted groups (34%).

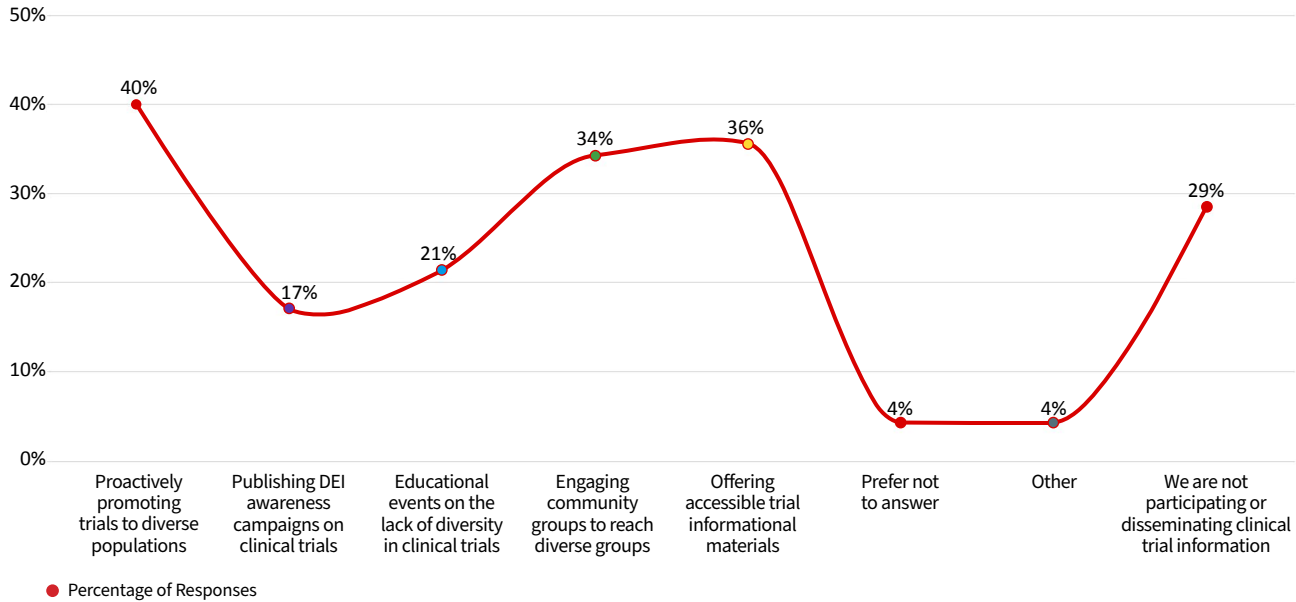
<sup>5</sup> We based our understanding of patient advocacy organizations’ clinical trial efforts on following survey question: “Does the organization deliberately engage in any of the following to ensure the participation of a diverse rare disease population in the clinical trial process?” (#14).

*“Yeah, I will say I don’t think we have I think we need someone who is like specifically focused on DEI right now, like with a staff of 5. I think everyone just has their own hands full in so many things that the DEI efforts, I think, don’t get the attention that they deserve, or that they need. So I guess I’ve sort of been deemed the DEI person at our organization now.” – INTERVIEW PARTICIPANT*

**Figure 17. Clinical Trial Participation Strategies**

Does the organization deliberately engage in any of the following to ensure the participation of a diverse rare disease population in the clinical trial process? (Select all that apply.)

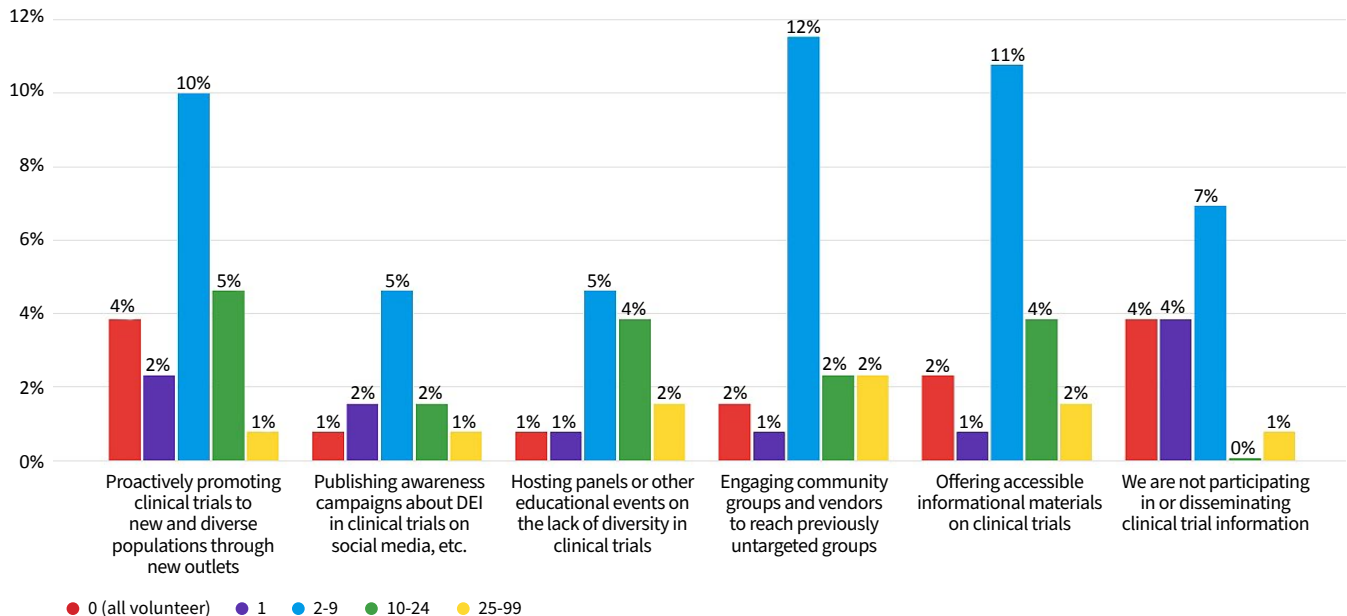
70 Responses



**Figure 18. Clinical Trial Participation Strategies Response by Number of Employees/Volunteers at the Organization**

Does the organization deliberately engage in any of the following to ensure the participation of a diverse rare disease population in the clinical trial process? (Select all that apply.)

70 Responses







## 6. DEI Evaluation Efforts<sup>6</sup>

### DEI Evaluation Efforts Key Findings:

- The most popular strategy for measuring the respondent’s organization’s DEI effectiveness was collecting appropriate demographic information from their employees/volunteers.
- Similar to communication methods, respondents and key informant interview participants indicated the need to measure demographic information that was readily accessible and cost effective such as their hires, and representation of board of directors.
- Still other organizations indicated they were not measuring the effectiveness of their DEI efforts.
- Overall, survey respondents and key informant interview participants indicated they were not satisfied with their current progress but are actively initiating changes.
- Higher-level employees were less favorable of their organization’s DEI efforts.

### DEI Evaluation Efforts Recommendations:

- As a part of employee/volunteer intake process, create a brief demographic survey.
- Periodically update demographic information for patients, employees/volunteers.
- Create an “Effective DEI Evaluation Guide” as a lay resource that organizations can use to assist with creating measurable evaluation efforts.
- Assess current DEI efforts and include metrics within the organization’s strategic plan.
- Provide guidance on how to develop organization-wide outcomes that are relevant to organization mission and measurable to monitor the effectiveness of DEI-focused initiatives.
- Develop a framework for growing board/ leadership representation.
- Create a framework for building DEI into an organization’s strategic plan.

Respondents were asked to identify how their organization measures the effectiveness of their DEI efforts. Many respondents indicated their organization did not currently measure the effectiveness of their DEI efforts (37%) followed by others who identified their efforts at capturing their employee/volunteer demographics as a method of measurement (35%). In addition, others identified quantifying the representation of their board of directors as an indicator (30%), and tracking their research participation (i.e., grant recipients, natural history database, clinical trials) (24%). Survey respondents were also asked to evaluate their organization’s DEI efforts and to identify the biggest barriers to improving DEI efforts within the organization. Many organizations identify that they are in the process of initiating some changes but have a long way to go (36%), while others indicate they are satisfied with where their organization is (13%). Respondents who mentioned “other” indicated, “DEI is at the heart of our organization’s mission.”

<sup>6</sup> We based our understanding of patient advocacy organizations’ DEI evaluation efforts by combining the following survey questions: “What metrics do you use to measure the effectiveness of the organization’s DEI efforts?” (#26), “How would you evaluate the organization’s DEI efforts?” (#27), and “What are the biggest barriers to improvement within the organization as it relates to DEI?” (#28). We based our understanding of patient advocacy organizations’ DEI evaluation efforts by combining the following survey questions: “What metrics do you use to measure the effectiveness of the organization’s DEI efforts?” (#26), “How would you evaluate the organization’s DEI efforts?” (#27), and “What are the biggest barriers to improvement within the organization as it relates to DEI?” (#28).



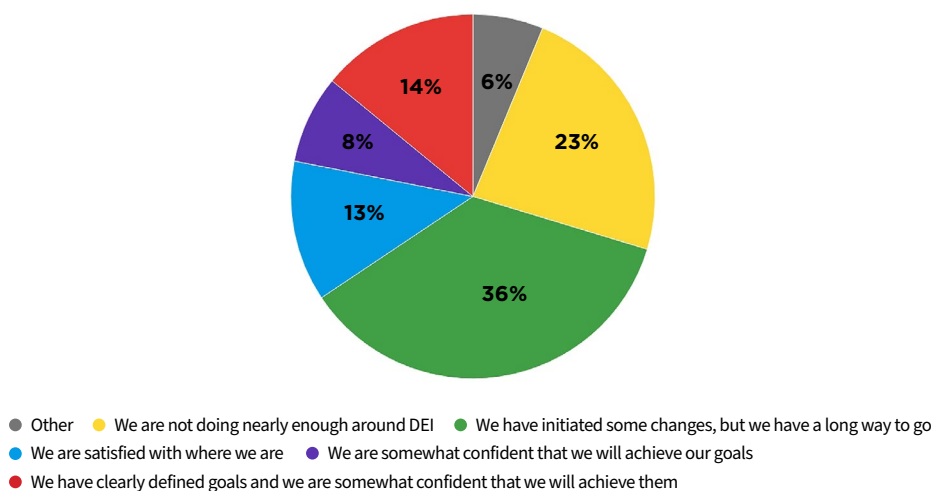
*“But unfortunately, we don’t have the diversity in the organization that we want, and that we should have, and that’s the reality. I tell everybody it’s a marathon, but you know we talk about this a lot. We talk about this in our staff meetings, and we talk about the people we’re missing, and what can we do? Unfortunately it’s just so hard for us to keep our heads above water with where we are, but we know we’re missing so many people that could use us and so many families that need support.” – INTERVIEW PARTICIPANT*

The most significant barriers to improving DEI efforts centered around measuring effectiveness (45%), setting tangible internal goals for improving DEI (43%), greater representation on the board of directors (38%), and making DEI a strategic focus for our leadership (37%).

**Figure 19. Organization DEI Evaluation**

How would you evaluate the organization’s DEI efforts?

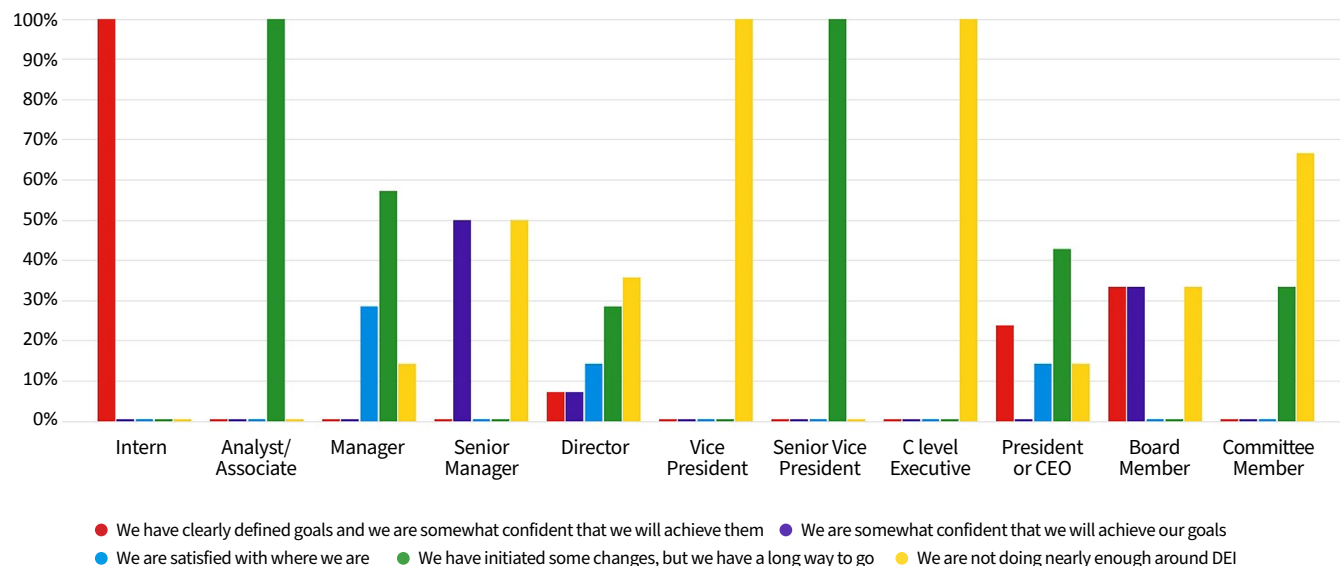
64 Responses



**Figure 20. Organization DEI Evaluation by Employee/Volunteer Title**

How would you evaluate the organization’s DEI efforts?

64 Responses



# Summary Recommendations

We recommend the following summary recommendations:

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## **Overall Organizational Commitment and Accountability for DEI Recommendations:**

1. Create a job description specifically related to DEI.
2. Create DEI specific accountability metrics across organization activities to guide efforts.
3. Create a DEI mission and vision for the organization.
4. Create a DEI webpage that assesses the organization's DEI efforts throughout the year.

## **DEI Initiatives and Activities Recommendations:**

5. Create resources that identify potential opportunities to engage diverse individuals in a creative manner.
6. Conduct a needs assessment with staff to identify areas of interest for targeted development opportunities.
7. Post job/volunteer opportunities in various spaces based on the target audience (HBCUs, Black Nurses Association, etc.).
8. Identify free, reduced-cost, or paid DEI workshops for staff engagement.
9. Create a DEI toolkit for accessible websites, social media, etc., for patient advocacy organizations.

## **DEI Communication Strategies Recommendations:**

10. Create a DEI checklist that offers guidance to ensuring that websites include social media, and other informational material reflect all areas of DEI (imagery, font size, wording, etc.).
11. Connect with diverse organizations across social media platforms that may not be specific to your disease.

## **Demographic Information Collection Efforts Recommendations:**

12. Create easy, accessible opportunities for individuals to leave their contact information when accessing resources on the website.
13. Create a quick demographic survey template that can be used across the organization's efforts.
14. Create a "How to Evaluation Guide" as a lay resource that organizations can use to implement evaluation strategies across their organization.

## **Pursuing Diversity in Clinical Trials Recommendations:**

15. Post clinical trial information on patient advocacy organization's websites, social-media, and other public-facing communication methods.
16. Create a lay guide that provides an overview of a clinical trial and how to participate.
17. Provide opportunities for the public to participate in forums that serve as an educational tool for rare disease families to address clinical trial information.

## **DEI Evaluation Efforts Recommendations:**

18. As a part of employee/volunteer intake process, create a brief demographic survey.
19. Send out an annual brief demographic survey that can be inserted in a quarterly newsletter.
20. Create an "Effective DEI Evaluation Guide" as a lay resource that organizations can use to assist with creating measurable evaluation efforts.
21. Assess current DEI efforts and include metrics within a strategic plan.
22. Engage in targeted recruitment efforts of underserved/minority populations at the beginning of projects that drive inclusion practices throughout organizations.

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*“I’d say our priority right now is launching the different languages to increase the representation in the registry. Our registry is really where we do all. It’s where we get a lot of our outreach efforts and where we get all of our data to put in our reports and such. Seeing just a lack of data from different parts of the world that we really like to include, so I think that’s sort of our first priority. I would also say just creating some initiatives and some programming that is more specific to diverse groups within the United States.”*

– INTERVIEW PARTICIPANT

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## Survey Limitations

The findings in this project should be understood based upon limitations. The demographics of our sample are very limited and not generalizable to a larger demographic group. Our sample included a limited number of respondents who identified as interns, entry-level analysts, associates, senior managers, or volunteers. Most respondents indicated they were C-level suite employees which would not represent the larger scope of employee opinions on DEI. In addition, the majority of respondents were 35-44 years old, had higher levels of educational attainment,

female, and White. Moreover, most organizations were headquartered in the South, had an annual revenue of \$100,000 - \$500,000, and had between 2-9 employees. Also, the analyses of the results were limited based on the small sample size; however, the results may help create more meaningful strategies for broadly diversifying the rare disease field. Lastly, key informant individual interviews with patient advocacy organization representatives yielded a small percentage of the larger patient advocacy organization ecosystem.

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## APPENDIX

# Diversity, Equality, and Inclusion Efforts in Rare Disease Organizations **Survey**

Welcome! Thank you for participating in the Diversity, Equality, and Inclusion (DEI) Efforts in Rare Disease Organization Survey conducted by the Black Women’s Health Imperative/Rare Disease Diversity Coalition and developed by Upequity.

### **About Black Women’s Health Imperative/Rare Disease Diversity Coalition/Upequity**

The Black Women’s Health Imperative (BWHI) is a national non-profit organization dedicated to advancing health equity and social justice for Black women, across the lifespan, through policy, advocacy, education, research, and leadership development. The RDDC is an initiative launched by BWHI to address the extraordinary challenges faced by rare disease patients of color. You can find more information about these organizations at <https://www.rarediseasediversity.org>. Upequity is a national nonprofit research and pilot lab focused on advancing systems and policy changes to create equal access to quality, affordable healthcare for those with rare or serious health conditions. You can find more information about Upequity at <https://www.upequity.org>.

The goal of this project is to conduct an audit and analysis of the current state of rare disease patient organizations—with a focus on efforts related to outreach, education, and support of rare disease patients of color. This survey will ask you questions about:

- Diversity in rare disease organizations
- Current organizational efforts to address diversity, equity, and inclusion
- Suggestions for improving diversity, equity, inclusion efforts within rare disease organizations

Your answers will help us better understand diversity in rare disease and use this information to create a report on DEI in rare disease. It takes about 15 to 20 minutes to answer these questions. There are no right or wrong answers to the questions. You can choose not to answer any question for any reason. Your responses will be confidential. By continuing the survey, you acknowledge your consent to participate. We appreciate your time and feedback!

**How did you find out about this survey?**

**(Select all that apply.)**

- Rare Disease Diversity Coalition (RDDC)
- Upequity
- Global Genes
- Every Life Foundation
- National Organization for Rare Disorders (NORD)
- Social media
- Family/friends
- Other (Please specify) \_\_\_\_\_
- Prefer not to answer

**The following questions are about the organization you are employed/volunteer at.**

**Where is the organization headquartered?**

- |  |   |
|--|---|
| <input type="radio"/> Alabama              | <input type="radio"/> New Jersey                    |
| <input type="radio"/> Alaska               | <input type="radio"/> New Mexico                    |
| <input type="radio"/> Arizona              | <input type="radio"/> New York                      |
| <input type="radio"/> Arkansas             | <input type="radio"/> North Carolina                |
| <input type="radio"/> California           | <input type="radio"/> North Dakota                  |
| <input type="radio"/> Colorado             | <input type="radio"/> Ohio                          |
| <input type="radio"/> Connecticut          | <input type="radio"/> Oklahoma                      |
| <input type="radio"/> Delaware             | <input type="radio"/> Oregon                        |
| <input type="radio"/> District of Columbia | <input type="radio"/> Pennsylvania                  |
| <input type="radio"/> Florida              | <input type="radio"/> Rhode Island                  |
| <input type="radio"/> Georgia              | <input type="radio"/> South Carolina                |
| <input type="radio"/> Hawaii               | <input type="radio"/> South Dakota                  |
| <input type="radio"/> Idaho                | <input type="radio"/> Tennessee                     |
| <input type="radio"/> Illinois             | <input type="radio"/> Texas                         |
| <input type="radio"/> Indiana              | <input type="radio"/> Utah                          |
| <input type="radio"/> Iowa                 | <input type="radio"/> Vermont                       |
| <input type="radio"/> Kansas               | <input type="radio"/> Virginia                      |
| <input type="radio"/> Kentucky             | <input type="radio"/> Washington                    |
| <input type="radio"/> Louisiana            | <input type="radio"/> West Virginia                 |
| <input type="radio"/> Maine                | <input type="radio"/> Wisconsin                     |
| <input type="radio"/> Maryland             | <input type="radio"/> Wyoming                       |
| <input type="radio"/> Massachusetts        | <input type="radio"/> Puerto Rico                   |
| <input type="radio"/> Michigan             | <input type="radio"/> U.S. Virgin Islands           |
| <input type="radio"/> Minnesota            | <input type="radio"/> American Samoa                |
| <input type="radio"/> Mississippi          | <input type="radio"/> Northern Mariana Islands      |
| <input type="radio"/> Missouri             | <input type="radio"/> Guam                          |
| <input type="radio"/> Montana              | <input type="radio"/> Other (Please specify.) _____ |
| <input type="radio"/> Nebraska             | _____   |
| <input type="radio"/> Nevada               | _____   |
| <input type="radio"/> New Hampshire        | <input type="radio"/> Prefer not to answer          |

**What is your current title at the organization?**

- Intern
- Entry level
- Analyst/Associate
- Manager
- Senior Manager
- Director
- Vice President
- Senior Vice President
- C-level executive (CIO, CTO, COO, CMO, CSO, CFO)
- President or CEO
- Board Member
- Committee Member
- Volunteer
- Other (Please specify.) \_\_\_\_\_

**How many people are employed at the organization?**

- 0 (all volunteer)
- 1
- 2-9
- 10-24
- 25-99
- 100-499
- 500-999
- 1000-4999
- 5000+

**What is the organization's annual revenue?**

- Under \$10,000
- >\$10,000-\$50,000
- >\$50,000-\$100,000
- >\$100,000-\$500,000
- >\$500,000-\$1 million
- >\$1 million-\$5 million
- >\$5million -\$10 million
- Over \$10 million
- Unsure

**How many hours/week do you usually work or volunteer at this organization?**

- Less than 35 hours a week
- 35 hours a week or more



**The following questions are about the DEI efforts at the organization you are employed/volunteer at. Over the past 12 months, which steps has the organization taken to achieve diversity in recruiting employees volunteers (Select all that apply.)?**

- Using data insights to uncover and address potential biases in the process
- Ensuring job postings are worded to eliminate bias
- Hiring from diverse and varied geographic locations
- Offering bias training for recruitment/hiring teams
- Posting jobs in non-traditional outlets
- Hiring more part-time employees
- Proactively prioritizing candidates from less traditional backgrounds
- Partnering with community groups and/or vendors to proactively reach marginalized candidates
- Replacing mandatory education or experience requirements with relevant skills or core competencies to reach a broader pool of eligible candidates
- Hiring employees on a fully remote basis
- Engaging volunteers on a fully remote basis
- Involving multiple/diverse stakeholders in decision-making on new hires
- Standardized interview questions and rubrics
- Anonymized resume review to reduce bias
- Hiring employees who have been out of the workforce for an extended period of time
- Engaging volunteers who have been out of the workforce for an extended period of time
- Including DEI in mission/vision
- We are not changing our hiring efforts to be more diverse and inclusive this year
- Other (Please specify.) \_\_\_\_\_

**What inclusion measures has the organization introduced over the past 12 months (Select all that apply.)?**

- Formalized or updated a DEI strategy at the organization
- Created DEI awareness campaigns (promoting DEI on social media, company website, DEI resources, etc.)
- Created educational resources that are specifically geared towards minorities and other traditionally underserved communities
- Improved underserved-community resources (educational material on rare diseases geared towards minorities, etc.)
- Created DEI engagement programs with the community (DEI advisory council, community advisory council, corporate advisory councils that include community members, etc.)
- Offered educational materials at accessible reading levels, in different languages, etc.
- Provided resources on how employees and/or volunteers can get involved (volunteering, donations, community events, etc.)
- Updated or reviewed code of conduct to specifically address DEI
- Created or reviewed DEI policies and provided them to employees, volunteers and board members
- Introduced or expanded mandatory DEI training for employees and/or volunteers
- Made actionable changes to hiring policies
- Increased support for employee/volunteer-driven activities, such as Employee/Volunteer Resource Groups
- Offered resources/information for additional education or support around DEI
- Introduced or expanded volunteer time off
- Conducted employee/volunteer surveys focused on DEI
- Conducted conversations with community leaders
- Identified grants to support equity learning
- Followed community and diverse groups on social media
- Adopted language that was not watered down so as not to offend the reader
- Attended diversity workshops
- We have not introduced any inclusion measures over the last 12 months
- Other (Please specify.) \_\_\_\_\_

**How is the organization currently communicating their efforts around DEI (Select all that apply.)?**

- Adding our DEI efforts to our home page or website
- Posting a DEI statement on our website
- Hiring outside organizations specializing in DEI to lead discussions and training with employees/volunteers
- Offering or requiring consistent DEI training to employees/volunteers
- Offering training on DEI to Board of Directors
- Offering training to voluntary community leaders
- Creating diverse informational materials (photos, language, translation)
- Purchasing DEI software for employee/volunteer awareness and training
- Communicating DEI efforts in company-wide channels such as e-newsletters, etc.
- Highlighting DEI efforts on our social media channels
- Updating our employee/volunteer handbook to reflect our DEI efforts
- We are not communicating about our efforts around DEI
- Other (Please specify.) \_\_\_\_\_

**Does the organization deliberately engage in any of the following to ensure the participation of a diverse rare disease population in the clinical trial process? (Select all that apply.)**

- Proactively promoting clinical trials to new and diverse populations through new outlets
- Publishing awareness campaigns about DEI in clinical trials on social media, etc.
- Hosting panels or other educational events on the lack of diversity in clinical trials
- Engaging community groups and vendors to reach previously untargeted groups
- Offering accessible informational materials on clinical trials
- We are not participating in or disseminating clinical trial information
- Prefer not to answer
- Other (Please specify.) \_\_\_\_\_

**Does the organization collect demographic information (race/ethnicity, geographical location, education, etc.) for the community (ies) it serves?**

- Yes
- No
- Unsure
- Other (Please specify.) \_\_\_\_\_
- Prefer not to answer

**Does the organization regularly review this demographic information (race/ethnicity, geographical location, education, etc.) and use it to inform efforts to improve the reach of its services/programs to new and diverse groups?**

- Yes
- No
- Unsure
- Other (Please specify.) \_\_\_\_\_
- Prefer not to answer

**Does the organization offer any of the following services (Select all that apply.)**

- Culturally-informed advocacy efforts to teach diverse communities how to be an advocate in rare disease (Awareness/education on how to ask or even challenge a physician, cultural competence training, resources addressing advocacy)
- Programs for diverse caregivers/care partners
- Closed captioning/translation during programming
- Educational programming in languages other than English
- Available website translations in languages other than English
- None of these

**Thinking about the strategy and goals of the organization you are employed/volunteer at, select the answer that most closely applies...**

If the organization publicly communicates information about its diversity goals, where is the information published (Select all that apply.)?

- Board meetings
- Public website
- Annual report
- Internal company communication channels such as e-newsletters
- Social media
- Public relations communications (press releases, media outreach)
- Organization does not currently publicly communicate diversity goals
- Unsure
- Other (Please specify.) \_\_\_\_\_

**Thinking about the roles and responsibilities within the organization you are employed/volunteer at, select the answer that most closely applies... Organization's leaders communicate about diversity (Select all that apply.)**

- Whenever discussing the organization's business strategy and goals
- In regular communications that focus on diversity & inclusion
- On ad hoc basis
- Very infrequently or not at all

**The following statement best describes accountability for diversity, equity & inclusion within the organization (Select all that apply.)**

- Leaders and team are tasked with specific DEI goals
- Leaders and team are provided time by the organization to devote to DEI goals
- Leaders' progress toward meeting their diversity & inclusion goals and goals are regularly measured and evaluated
- Progress towards meeting diversity & inclusion goals influences performance evaluation, promotion and compensation outcomes for leaders
- Progress towards meeting diversity & inclusion goals influences performance evaluation and compensation outcomes for all employees/volunteers
- Unsure
- None of the above

**The diversity, equity, and inclusion program leader is**

- A staff member who has a variety of other non-diversity related responsibilities and priorities
- A board member or committee on staff who have other roles within the company
- A dedicated program leader who reports under other senior executives
- A dedicated program leader who is considered a peer to other C-Suite executives
- My organization does not have a clear leader for diversity & inclusion efforts
- Other \_\_\_\_\_

**Thinking about the programs in place at the organization you are employed/volunteer at, select the answer that most closely applies... The organization has programs in place to (Select all that apply.)**

- Recruit diverse candidates
- Develop a pipeline of diverse leaders
- Provide targeted development opportunities for diverse employees/volunteers
- Demonstrate impartiality in performance and compensation decisions
- Unsure
- Other (Please specify.) \_\_\_\_\_

**Thinking about the employee/volunteer experience at the organization, select the answer that most closely applies... Employees/volunteers at the organization demonstrate a commitment to creating an inclusive environment.**

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

**Leadership at the organization demonstrates a commitment to creating an inclusive environment.**

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

**What metrics do you use to measure the effectiveness of the organization's DEI efforts (Select all that apply.)?**

- Hires
- Retention rate and exit rate
- Employee/volunteer demographics
- Compensation increases and promotion rates
- Employee/volunteer experience surveys
- Offboarding interviews
- Employee/volunteer focus groups qualitative feedback
- Qualitative check-ins with employees/volunteers
- Representation of board of directors
- Participation in research (ex. grant recipients, Natural History Database, clinical trials)
- We are not measuring the effectiveness of our DEI efforts
- Unsure
- Other (Please specify.) \_\_\_\_\_

**How would you evaluate the organization's DEI efforts?**

- We have clearly defined goals and we are somewhat confident that we will achieve them
- We are somewhat confident that we will achieve our goals
- We are satisfied with where we are
- We have initiated some changes, but we have a long way to go
- We are not doing nearly enough around DEI
- Other (Please specify): \_\_\_\_\_

**What are the biggest barriers to improvement within the organization as it relates to DEI (Select all that apply.)?**

- Communicating DEI goals and progress to employees/volunteers
- Setting tangible internal goals for improving DEI
- Measuring the effectiveness of our efforts
- Changing our hiring, onboarding, and professional growth opportunities to align with our goals
- Inviting employees/volunteers to contribute to our efforts
- Greater representation on board of directors
- Increasing diversity of community leaders
- Making DEI a strategic focus for our leadership
- Improving the diversity of our leadership
- Engaging employees/volunteers to contribute to and participate in DEI efforts
- We do not need to improve our DEI
- Other (Please specify.) \_\_\_\_\_

**The following questions are about your demographics. Which category below includes your age?**

- 18-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65-74 years
- 75 years or above
- Prefer not to answer

**How do you describe your gender identity? (Select all that apply.)**

- Male
- Female
- Gender variant/Non-conforming
- Agender
- Gender fluid
- Gender queer
- Transgender Female
- Transgender Male
- Not listed (Please specify) \_\_\_\_\_
- Prefer not to answer

**Which of the following categories describe you? (Select all that apply.)**

- American Indian or Alaska Native
- Asian
- Black, African American, or African
- Hispanic, Latino, or Spanish
- Middle Eastern or North African
- Native Hawaiian or Other Pacific Islander
- White
- Afro-Caribbean
- None of these fully describe me (Please specify.) \_\_\_\_\_
- Prefer not to answer

**What is the highest degree or level of school you have completed?**

- Less than high school
- Some high school
- High school diploma or GED
- Some college
- Associate's degree or technical school
- Bachelor's degree
- Master's, Professional, or Doctorate degree
- Prefer not to answer

**If you would like the organization you are employed/volunteer at to be included in a \$2,500 drawing based on your survey participation, please provide the organization's name. If you are more comfortable emailing the organization's information, you can email us at ContactUs@upequity.org. The organization's information will remain confidential. Survey results will not include organizational names and data will not be linked to employee/volunteer responses.**

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**If you are interested in participating in individual interviews for this project, please provide your contact information below (name, email, telephone number). Contact information will remain confidential. Survey results will not include contact information and data will not be linked to employee/volunteer responses.**

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*“I walk into a room, and I wanna see all sorts of different people around me. And I’m starting to see that in the rare disease space option.”* – INTERVIEW PARTICIPANT

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*“I think we’re doing our best. There’s still always work that can be done, more so on the leadership side. But, I mean with me and in my team, I feel very lucky with the different, I guess kind of backgrounds that we all come from to be able to provide the effect that we do. And as far as the leadership is concerned. There are some things that it’s just kind of disappointing when things are brought forth, and don’t really see any progress in it, or having kind of DEI efforts within kind of like a working group but not.”*

– INTERVIEW PARTICIPANT

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*“Finding people where they’re at and reaching them where they’re at, too, as far as like even our programming, our toolkits, or things like that, I do wish that sometimes I had more time to be able to work with some more organizations a little bit more intensely if they need it, especially our grant opportunities that we don’t have someone who can really help. Others navigate and fill those out, and we try to do different lunch and learn opportunities to kind of help teach those skills. But then again, it’s still depending on the time of where you are in the world, and everything like that. I would love to get out and kind of not always be on Zoom too, but instead find different organizations and people where they’re at in their in their communities and doing more research about how they like to be communicated with, and find what’s important to them and how we can incorporate them or to be a bigger voice.”* – INTERVIEW PARTICIPANT

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*“To me personally, you know, diversity to me just basically represents our community as a whole. I think it’s important to represent men and women, people of color, whatever gender you identify with equally and provide the same services to all of those people. You know the past few years have been difficult for me personally, for my family personally, because I feel like the concept of diversity, and the acceptance of diversity is just being spit on. I feel like as a patient advocacy organization that it’s our responsibility to provide services and represent every facet of people regardless of you know where they come from, what they look like, and how they identify”* – INTERVIEW PARTICIPANT

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*“This is what’s so unbelievable about the rare space, right? It’s not a matter of whether you will get or know someone with a rare disease, but it’s a matter of when, because statistically one out of 10 people have a rare disease”* – INTERVIEW PARTICIPANT

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*“So when I when I look at the rare disease space you know it doesn’t matter whom I’m talking to. For me, it’s about saying listen, you know I don’t care if you’re a man if you’re a woman, if you’re working, where you’re from, how you identify at some point in your life. You’re either gonna have a family member with a rare disease, you’re gonna have a rare disease, or you’re gonna have a friend with a rare disease.”*

– INTERVIEW PARTICIPANT

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