

**Diversity, Equity, and Inclusion (DEI) at Center for  
Information and Study on Clinical Research  
Participation (CISCRP)**

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## **Executive Summary**

### **Project Summary**

The Center for Study and Information on Clinical Research Study (CISCRP) is a non-profit organization dedicated to providing unbiased educational materials to help the public make informed decisions on clinical research studies. CISCRP mainly works with pharmaceutical companies based in the United States and in Europe to provide participants with services that translate scientific documents into plain text summaries at the 7th grade reading level.<sup>4</sup> Although CISCRP excels at providing external products through a robust DEI focused lens, they wish to improve their internal DEI environment to better reflect their external services.<sup>4</sup> To increase their internal DEI practices, CISCRP formed a 13-member DEI council as well as created an organizational DEI statement.<sup>4</sup> Furthermore, CISCRP employed the help of a consultant to help identify areas CISCRP can improve as an organization to increase their internal DEI practices.<sup>4</sup>

### **Problem Statement**

The consultant identified five main areas that CISCRP can improve as an organization within their internal DEI environment: increasing racial and ethnic representation within CISCRP, educating employees and raising awareness in DEI, increase age and generational diversity within the organization, communicating to staff and stakeholders around DEI practices, and implementing policies and practices focused on DEI.<sup>4</sup> CISCRP is currently working with another consultant to address these challenges and improve their DEI programming.<sup>4</sup> Our role in this project is to identify best practices in implementing DEI initiatives through literature review, competitor analysis, and interviews with industry leaders in DEI before making our own strategic recommendations.

## Internal and External Analysis

Through our research into CISC RP's competitors, few companies had initiatives to increase their external DEI strategies and even fewer had initiatives targeted at increasing their internal DEI practices.<sup>16-20</sup> Out of the companies with internal DEI initiatives, we found most employed a DEI manager to lead DEI efforts, created DEI councils, and implemented training targeted at improving DEI within the workforce.<sup>16=20</sup> We interviewed two industry leaders in DEI, both from large medical centers that placed heavy emphasis on how DEI impacts their employees and their patients.<sup>22-23</sup> Both leaders mentioned barriers in determining best practices regarding DEI strategies internally and externally.<sup>22-23</sup> However, both leaders emphasized the importance of measuring progress towards DEI and receiving buy-in from the community.<sup>22-23</sup> Another theme that emerged is to have the workforce be representative of the population that the organization serves.<sup>22-23</sup> If this cannot be achieved, employees and leaders in the organization should strive to learn cultural humility and competence.<sup>22-23</sup> To better understand the current internal climate at CISC RP and the feasibility of our recommendations, we interviewed five employees to talk about their thoughts on the internal DEI practices at CISC RP and areas of improvement. Through our interviews with CISC RP employees, we found that CISC RP has a positive and open work culture where everyone is willing to learn together.<sup>24-28</sup> Additionally, employees mentioned positive buy-in from leadership, specifically pertaining to increasing the organization's internal DEI, and contribution of financial resources as strong assets at CISC RP.<sup>24-28</sup> CISC RP employees cited a gap in the valuing of perspectives between remote and in-person employees, slow pace of progress, and the limitations of being a small organization with low turnover rates and restrictions on workforce expansion as barriers to progressing internal DEI initiatives.<sup>24-28</sup>

## **Recommendations**

Based on the information gathered from our interviews and competitor analysis, we provided CISCRP with the following recommendations to better align their internal DEI environment with their external practices.

1. Engage the whole organization in DEI Efforts by creating more opportunities to include remote employees.
2. Developing a DEI scorecard with KPIs that is able to measure the organization's progress on their DEI initiatives.
3. Expand and standardize DEI training to not only include anti-bias training, but to include the addition of cultural competency training, leadership development, and skill training, particularly for individuals from diverse backgrounds.

## **Conclusion**

CISCRP as an organization excels at providing services centered around cultural humility through a DEI lens, however barriers such as the size of the organization and the hybrid model of the workforce have impeded current progress surrounding meeting their internal DEI goals.<sup>24-28</sup> Our recommendations focus on adopting practices from our interviews and literature review to better utilize the strengths of the organization and close existing gaps to improve internal DEI efforts.

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## **Introduction and Background**

The Center for Information and Study on Clinical Research Participation (CISC RP) is a non-profit organization founded in 2003 by Ken Getz with the aim to provide unbiased information to the public regarding clinical research by partnering with pharmaceutical companies.<sup>1</sup> They also provide educational materials surrounding clinical trial participation, simplifying the language used in clinical studies and providing participants with the information they need to know to make informed decisions.<sup>2</sup> CISC RP strives to educate and empower various stakeholders about clinical research trials. In doing so, they bring together patients, communities, healthcare professionals, policymakers, and the media. By emphasizing the importance of participation in trials, they aim to address current barriers and misconceptions surrounding clinical research to further advance

public health and medical innovation. This mission underscores the organization's commitment to bridging the gap between research institutions and the broader community, fostering a sense of hope and trust in creating medical progress.<sup>1</sup> The current goals and objectives of this organization include de-mystifying the clinical trial process and forming connections between researchers and prospective participants. They seek to accomplish these goals through educational initiatives and direct community outreach.<sup>3</sup>

CISCRP's vision reflects a future where there is widespread awareness and appreciation for the contributions of research participants, leading to improved health outcomes and treatments for all.<sup>1</sup> They work to raise awareness, enhance experiences, and strengthen communication and relationships among participants, research professionals, and the public. The values of this organization reflect their commitment to transparency, trust, and cultural competency. CISCRP also exemplifies a strong commitment to Diversity, Equity, and Inclusion (DEI) and provides resources about the importance of these concepts in clinical research.<sup>1</sup>

### **Objectives and Main problems**

The goals of this project are twofold, to identify unique service offerings from competitors that enhance DEI and support research participants, and to identify best practices in DEI that can be applied internally to CISCRP. CISCRP excels in its external DEI offerings from a product and relationship perspective but would like to align its internal environment with its external practices.<sup>4</sup> Initially, many individuals at CISCRP were white or white-presenting.<sup>4</sup> Although this has changed over time, there is still much work to be done and CISCRP's employees have voiced increased interest in DEI.<sup>4</sup> Consequently, CISCRP has brought on a temporary consultant and has implemented a 13 person DEI committee to address challenges at their organization.<sup>4</sup> Five specific areas of improvement were identified: racial and ethnic representation, DEI education and awareness, age and generational diversity, communication, and the need for review of



policies and practices through a DEI lens.<sup>4,5</sup> To address these issues, CISC RP has formed a DEI statement, conducted lunch and learns, participated in workshops, and used anti-bias toolkits in addition to hiring a new consultant.<sup>1,4,5</sup> Our goal in this project is to assist CISC RP in this process by identifying strategies they can use to improve DEI internally, and ways they can improve their external products based on the competitive landscape.

### **Product and Service Categories**

Center for Information and Study on Clinical Research Participation (CISC RP) is a non-profit organization focusing on informing the public about clinical research and developing health literacy resources.<sup>1</sup> They mainly offer services in health communication, research, and content licensing which are summarized in Figure 1.<sup>2</sup>

#### ***Health Communication***

Their most prevalent and revenue-producing service, the health communication service, translates scientific documents, often filled with scientific jargon, into plain-text language writing at a 7th-grade reading level.<sup>4</sup> Additionally, CISC RP works with contracted companies, most commonly pharmaceutical companies, to ensure the documents and information they provide are unbiased. The range of documents and materials that CISC RP translates currently includes trial results summaries, protocol synopses, informed consent forms, publication summaries, trial registry listings, Pediatric trial results supplements, educational material, and videos.<sup>2</sup> In addition to health communication translation, CISC RP also offers health communication services such as: assisting with trial participant communications, unbinding communications between participants and clinical trial personnel, creating website content centered around health communication, and hosting health literacy workshops.<sup>2</sup> One service that sets CISC RP apart from other companies/organizations that provide health communication services is its review panel.<sup>4</sup> Their review panel is composed of community members, advocates, patients, professionals, and

someone who has no knowledge of the topic to help decide if the information being presented is both equitable and understandable.<sup>4</sup>

### ***Scientific Research***

Another area in which CISCRP offers services is scientific research.<sup>2</sup> They offer services encompassing a wide range of research topics, including but not limited to pharmaceuticals, biotechnology, medical device companies, contract research organizations, and academic organizations, and in various stages of research study design. Their patient and care advisory board service aims at better understanding disease experiences and relaying feedback on research protocol designs through in-person or virtual round table discussions. CISCRP also conducts its own research through its perceptions and insights study, which is a global study they conduct every two years to gauge the public's perception of clinical research.<sup>2</sup> The results of this study can be offered to companies as a service to help them better frame their approach in clinical research. In addition to providing services to companies directly, they can help contracted companies engage their participants/patients to gain insight into the clinical trial and preferences throughout the process. This interactive workshop, the clinical trial journey workshop, can help contracted companies identify factors that are most important to their patients and address potential barriers to improve retention rates.<sup>2</sup>

### ***Content Licensing***

In addition to tailoring services to its clients, CISCRP creates its own content, such as brochures, videos, infographics, and videos, available for organizations to license, co-develop, customize, or sponsor. Their content centers around increasing health literacy, such as culturally competent brochures around the definition of placebos, what are clinical trials, and diversity in research. The diversity brochures are part of their greater patient diversity media campaign, which highlights awareness of the importance of diverse clinical trial participation especially as it pertains

to improving safer and more effective treatments for everyone.<sup>2</sup> They also offer three content packages for different interested organizations to license: diversity, pediatrics, and healthcare professionals (HCP) and researchers.<sup>2</sup>

## ***Events***

Currently, the center has two main educational initiatives: AWARE for All Events and Journey to Better Health.<sup>3</sup> Both initiatives seek to improve the public's knowledge of the clinical research process and foster trust. Journey to Better Health takes an innovative approach to this challenge by connecting directly with local communities through a mobile exhibit.<sup>3</sup> AWARE for All takes this program one step further by offering free healthcare screenings and connecting attendees to speakers from a wide variety of health-related backgrounds.<sup>3</sup>

## ***DEI***

Diversity, Equity, and Inclusion (DEI) are important features of both CISC RP's external service offerings and internal organizational goals.<sup>1,2,4</sup> Each of these tenants means something unique. Diversity can be thought of as how well different races, cultures, ethnicities, and genders are represented in an organization.<sup>6</sup> Equity broadly refers to parity between the individuals who make up these groups, that individual employees receive the same promotion rates and compensation regardless of their background.<sup>6</sup> Inclusion takes diversity one step further by reflecting on how diverse individuals are valued in an organization and made to feel that their opinions matter.<sup>6</sup> Because of this, it is important to identify methods that assess progress towards DEI at an organization and create a set of recommendations towards this goal.

Several general metrics are available to assess how well an organization accomplishes DEI principles, but each situation is unique. One strategy includes studying the rates of employees who leave the organization both voluntarily and involuntarily before comparing these to national

benchmarks.<sup>7</sup> Conducting exit interviews can be helpful in this process and can provide insight if employees do not feel safe.<sup>7</sup> Studying performance review from a quantitative perspective can also provide insight into unconscious bias in the organization and can provide opportunities for standardization.<sup>7</sup> Tracking and sharing the rates of promotion for diverse employees can encourage applicants from these backgrounds to apply to that organization.<sup>7</sup> It is also important to focus efforts on measuring the success of diverse employees throughout every aspect of the hiring process from job interviews to acceptances to leadership pipelines.<sup>7</sup> Achieving this may require diversification of employee sourcing and cutting back on referrals.<sup>6,7</sup> Additionally, reporting pay equity between employees and studying the sense of inclusion through quantitative surveys can help an organization assess its performance on DEI principles against national benchmarks.<sup>7</sup>

Ensuring that an organization has an effective DEI program and that employees feel safe has measurable benefits.<sup>8</sup> Studies measuring the effect of DEI have found that companies that espouse more gender, ethnic, and cultural diversity are more profitable, have better staff retention, and outperform companies with less diversity.<sup>8</sup> DEI is also important to job seekers and can be important in attracting top talent.<sup>8</sup> Despite these benefits, many organizations fail to implement successful DEI programs and there is high turnover in many Chief Diversity Officers (CDOs).<sup>7</sup> Several common pitfalls exist among companies that are unable to successfully implement DEI strategies: lack of dedicated resources, lack of organizational focus, and lack of longitudinal commitment.<sup>7</sup> Additionally, inconsistencies in how leadership and employees perceive success or current position in regard to DEI can hinder progress.<sup>7</sup> Furthermore, not all solutions are created equal and anti-bias training can sometimes have the opposite effect, reinforcing stereotypes.<sup>7</sup> Another key pitfall is understanding why DEI is important to a specific organization. DEI strategies fail when they rely on short-lived fads and when a solution is not tailored to the objectives and resources of a particular organization.<sup>7,9</sup> This is because achieving DEI at a company is not an endpoint, but rather a longitudinal process that needs to be sustained

indefinitely.<sup>9</sup> Once the organizational goals have been identified, specific and actionable changes need to be made with measurable results.<sup>9</sup> This process requires a review of existing policies to understand which groups fall through the cracks and requires incorporation of majority groups rather than excluding them.<sup>9</sup> Specificity and alignment with organizational goals are also key from a resource standpoint and it is important to budget what resources, both financial and employee wise, will be required to make these changes.<sup>7</sup> Encouraging a safe workplace and progress towards DEI at an organization is everyone's responsibility but the employees specifically in charge of the program should be knowledgeable, influential, and representative.<sup>8</sup>

### **Service Area**

CISCRP offers a portfolio of services to support patient engagement, clinical research education, and clinical trial participation for study volunteers, clinical research stakeholders, and sponsor organizations.<sup>2</sup> As an independent, neutral, non-profit organization dedicated to patient outreach and education, CISCRP is uniquely positioned to assist with a variety of activities including developing lay language clinical trial summaries, organizing and running patient advisory boards, conducting research to better understand public perceptions about research, and finding clinical trials.<sup>1</sup>

### ***Preferred Service Area***

While the majority of CISCRP's customers are in the United States, their current goals are to expand both domestically and internationally.<sup>4</sup> Currently, they have partners in Europe and Japan with goals of expanding to other nations.<sup>4</sup> Their mission and vision reflect a global perspective on clinical research participation and awareness.<sup>1,4</sup> By extending their services globally, CISCRP can better support biopharma and research companies in their clinical trials by ensuring participation

from a wide range of community groups. This expansion aligns with their mission and vision, which emphasize a global perspective on clinical research participation and awareness.

### ***Market and Demographics***

CISCRP offers a diverse array of services ranging from health communication, to research, and review panels.<sup>2</sup> On aggregate, they fall into the Clinical Trial Support and research services market which is valued at \$20.8 billion globally in 2022 and has an estimated compound annual growth rate (CAGR) of 7.50% between 2023-2030.<sup>10</sup> This market broadly includes anything ranging from managing a testing site to medications and recruiting/patient coordination.<sup>10</sup> The largest share of this market falls into the retention, recruitment, and monitoring segmentation with 44.5% of the total market in 2022 and a CAGR of 8.9%.<sup>10</sup> This is particularly advantageous to CISCRP since their plain language summaries, review panels, and emphasis on DEI in their products indirectly help their customers to retain and recruit study participants.<sup>4</sup> Growth in this specific market is driven by the rising demand for clinical trials outside of the United States, increased investment in research and development, expiration of pharmaceutical patents, competition from contract research organizations (CROs), remote monitoring, and rising rates of chronic disease.<sup>10</sup> Pharmaceutical companies make up the largest part of this sector and phase 3 clinical trials are the most lucrative.<sup>10</sup> These changes in the market are also advantageous for CISCRP since their largest customers are U.S based, and global, pharmaceutical companies that run clinical trials.<sup>4</sup> While the majority of CISCRP's consumers are in the USA or in Europe, they have broadened their reach to China and Japan as well.<sup>4</sup> Because each country has different cultural views surrounding patient empowerment in research, CISCRP must cater its approach to its customer.<sup>4</sup> CISCRP's reach into both U.S based, and global markets is important since the North American market represents a 50.1% share in 2022 and the Asia/Pacific region has the

highest CAGR due to increasing patient populations, administrative simplicity, and lower costs among other factors.<sup>10</sup>

CISCRP's current clients include Bayer, CSL Behring, Daiichi Sankyo, EMD, Gilead, Otsuka, Regeneron, and UCB with Eli Lilly as a client adjacent partnership.<sup>11</sup> However, CISCRP also maintains professional relationships with AbbVie, Astellas Pharma, Merck, Pfizer, and Sanofi.<sup>11</sup> According to CISCRP staff, CISCRP's strong emphasis on DEI in their product offerings and their patient advisory boards provide credibility to the research efforts of companies running clinical trials.<sup>12</sup> Cultivating a strong internal DEI culture is important to CISCRP in part since it provides legitimacy to their product offerings.<sup>12</sup> Many of their clients and organizations with whom they have professional relationships advertise their commitment to DEI and it is important for CISCRP to align with these values.<sup>13-15</sup> CISCRP's services are well received with market research demonstrating that 38% of customers report exceptional quality and 62% report above average quality.<sup>11</sup> Additionally, 77% of customers have taken advantage of patient input panels or advisory boards.<sup>11</sup> Among CISCRP's customers, plain language summaries are their most popular service followed by protocol synopsis and informed consent forms, a pattern that held true with their professional relationships as well.<sup>11</sup> Both plain language services and the review board are important to consumers since they ensure the absence of bias to patients.<sup>4</sup>

## ***Competitors***

Based on information provided by CISCRP and our own research, CISCRP's competitors can be categorized into two main areas as demonstrated in Figure 2.<sup>12</sup>

### Health Communication Services Competitors:

In the realm of Health Communication Services, companies such as Health Literacy Media, TrialScope, MMS Holdings, Syneos Health (which expanded its capabilities by acquiring Kinapse), Kateric, and various Medical Writing Companies including OPG and BOLD Science,

alongside Contract Research Organizations (CROs), stand out as key competitors to CISC RP.<sup>12</sup> These entities specialize in enhancing the clarity and accessibility of health information, ensuring regulatory compliance and transparency in clinical trials, offering digital marketing solutions tailored to healthcare, and crafting meticulous medical documents. Their collective efforts are dedicated to bridging the communication gap between healthcare entities and patients, thereby facilitating improved health literacy, patient engagement, and informed healthcare decisions. By providing these essential services, they directly compete with CISC RP's objectives of promoting awareness and understanding of clinical research among the public and also in meeting their clients' requirements etc.

#### Research Services Competitors:

In the sector of Research Services, organizations like Savvy, Reverba, CorEvitas (formerly HealthiVibe) etc., emerge as competitors by offering a broad spectrum of research and patient engagement services aimed at enhancing healthcare outcomes.<sup>12</sup> These companies focus on gathering in-depth patient insights, managing patient registries, generating real-world evidence, implementing strategic health communication, and advocating for health policy changes. Their work significantly contributes to the development of patient-centered healthcare strategies, ensuring that patient voices are heard in the research and development process.

#### Competitor Analysis

The clinical research support market can be sub-stratified into many different product offerings including laboratory support, clinical trial design, patient recruitment, scientific writing, and regulatory compliance among many others.<sup>10</sup> CISC RP shares this space with many organizations of all different sizes. The competitor analysis in Figure 4 was created by comparing CISC RP to five of its competitors based on similarities in product offerings. While there are many companies that share functionality with CISC RP, few companies provide the same breadth of clinical trial



participant centered services. Where MEDPACE excels in clinical trial specific services like strategic counseling, regulation compliance, and professional training, they do not provide the plain language services and advisory boards to legitimize clinical trials in the same way CISC RP can.<sup>16</sup> On the other hand, MEDPACE has developed integration through apps that support both providers and patients.<sup>16</sup> This is one idea that CISC RP could consider in the future as a way to provide participants with relevant information throughout a clinical trial. VOZ advisors share some similarities with CISC RP through its use of patient advisory panels and advocacy group databases, however they lack many features in terms of community engagement and plain language.<sup>17</sup> Health Literacy Media, like CISC RP emphasize the importance of plain language and culture specific content but differentiate themselves by offering professional training.<sup>18</sup> Offering professional training to clinical researchers is also an area where CISC RP could continue to expand in the future. Legacy health strategies also shares patient advisory boards and community engagement with an emphasis on strategic consulting but lacks the regulation compliance and trial databases offered by CISC RP.<sup>19</sup> Finally, Lumanity is able to offer regulation compliance and patient advisory boards but lacks plain language services.<sup>20</sup> Overall, CISC RP is able to stand out from its competitors through its diverse offering of services including plain language translations, content licensing, advisory boards, trial databases, regulation compliance, robust community engagement, and focus on DEI. Of these offerings, plain language services are the most unique and most valued by their customers, as discussed earlier in this report.<sup>11</sup> However, CISC RP could learn from its competitors by implementing app integration and professional training sessions to support both participants and researchers.

### ***SWOT Analysis***

As shown in Figure 5, CISC RP's strengths include their robust product offerings including plain language summaries, review panels, and culturally competent materials. These products facilitate CISC RP's ability to engage in direct community partnerships and support their external DEI focus.

However, CISC RP's current weaknesses include their internal DEI environment and the relatively small organizational size when compared to some of their competitors like MEDPACE.<sup>12</sup> Bringing CISC RP's internal DEI strategy in alignment with their external DEI strategy will be a valuable strategic objective in limiting their weaknesses and is the focus of this project.<sup>4</sup> If policies supporting DEI internally are not aligned with products that support DEI externally, then product offerings may suffer.<sup>4</sup> Opportunities for growth include changing legislation both in Europe and in the United States that require plain language summaries and outreach to diverse communities respectively.<sup>4</sup> CISC RP is well position to take advantage of this opportunity due to their product offerings. Growth in the clinical trial market following the COVID19 pandemic is also an opportunity for CISC RP since pharmaceutical companies are their primary customers.<sup>4</sup> Some threats to CISC RP include differing cultural beliefs towards transparency in clinical research in specific global markets as well as increased use of technology and app integration by competitors.<sup>4,16</sup>

### ***Porter's 5 Forces***

Analyzing the competitive landscape from the perspective of Porter's 5 Forces is also important and is demonstrated in Figure 6. When considering competitive rivalry, it is important to note that there is large market growth in this industry, especially post pandemic which can limit the pressures of competition.<sup>4,16</sup> This is especially important when considering the threats of substitution and the threat of new entrants since the market is so broad that different companies can find success offering vastly different products. For example, plain language communication, research services, and site management all fall under this market and different companies can tailor their product offerings to different parts of the clinical trial continuum.<sup>10</sup> However, relationships with both pharmaceutical companies and patients are important for companies to succeed in this market and CISC RP has several existing partnerships in both areas.<sup>4,11</sup> In this market, buyers (pharmaceutical companies) generally have more power than suppliers (research

service organizations) due to their ability to provide significant financial support.<sup>4</sup> However, as a supplier, CISC RP stands out through its ability to offer credibility and indirect patient recruitment to pharmaceutical companies.<sup>4,11</sup>

### ***DEI Strategy***

Information collected on the DEI strategy, both internally and externally, of CISC RP's competitors is demonstrated in Figure 7. From this figure, it is evident that many competitors do not have a publicly available internal or external DEI strategy. A common theme among external DEI offerings among CISC RP's competitors is their ability to recruit diverse patient populations for clinical trials, provide educational materials, or provide consulting through a DEI lens. In terms of internal DEI strategies, many competitors include statements of their values, have specific roles committed to DEI, or have training programs targeted towards this area.

### ***Key or Unique Features***

What sets CISC RP apart from its competitors is their focus on the educational aspect of clinical research participation. One key feature of this market is that organizations like CISC RP produce services that are largely intended for use by clinical trial participants but are marketed towards pharmaceutical companies. Another key feature of this market is that each country has its own set of regulations that change the way CISC RP is able to market its services and interact with pharmaceutical companies.<sup>4</sup> For instance, new legislation in both the United States and in Europe has recently mandated certifications for diversity in research and patient review panels respectively.<sup>4</sup> Since CISC RP has the unique ability to offer these services, it is well positioned to succeed in both these markets and provide legitimacy to companies running clinical trials. Additionally, unique cultural beliefs in each country regarding DEI and patient empowerment in research impact the way CISC RP presents itself. For example, while the United States is trending towards placing a strong emphasis on DEI and participant empowerment in research, these

practices are less prevalent in Japan where there is less demand for plain language summaries.<sup>4</sup> Another feature that makes CISCRP unique in this market is their direct outreach at community events and conferences. CISCRP attends conferences ranging from 200 to well over 1,000 attendees where they interface directly with people interested in research.<sup>3,4</sup> CISCRP also runs several campaigns and has an RV fitted like an interactive exhibition with fun activities that educate local communities on clinical trial participation and empowers community leaders.<sup>3,4,21</sup> This mobile exhibit, shown in Figure 3, also conducts research on community perspectives of clinical trials through surveys and has received outstanding community support.<sup>4</sup> In Fall 2023, the exhibit traveled to Philadelphia, PA and Baltimore, MD advocating for the importance of participation in clinical research and the critical need for more diverse representation.<sup>4</sup>

### ***Trends over time***

This industry has experienced substantial growth over time, particularly in recent years since the COVID19 pandemic for a variety of reasons including the expansion of remote participation and increased public knowledge of the research process.<sup>4</sup> CISCRP has also experienced significant growth since it began in 2003 with five employees working on plain language and trial results summaries as a response to a TIME magazine article that referred to research participants as guinea pigs.<sup>4</sup> Since that time, CISCRP grew to 30 employees just before the pandemic and is now supported by 50 employees, many of which work remotely.<sup>4</sup>

### ***Future Projects***

CISCRP has plans to expand both their external product services and their internal DEI environment in the coming months to years. Their mobile exhibition program has been a huge success and has demonstrated that community members retained research related information for at least 6 months.<sup>4</sup> Going forward, CISCRP hopes to offer this program as a multi-sponsorship opportunity for pharmaceutical companies so they can receive funding to bring this exhibit to a

broader range of communities and expand into rural areas.<sup>4</sup> Internally, CISCRP plans on developing a culture of DEI through lunch and learns, bringing on a full time consultant, improving their hiring practices, and creating conversations.<sup>4</sup>

### **Profiling Strategic Groups**

#### ***Most Important Stakeholders to Growth:***

- Pharmaceutical companies, because they commission and fund clinical research, making them primary consumers of CISCRP services.<sup>4</sup>
- Participants in clinical trials, as their experience and feedback are crucial for the improvement of clinical research practices and the validation of CISCRP's work.<sup>4</sup>

#### ***Connections and Reasons:***

- Pharmaceutical companies are connected to clinical trial participants through the research process. They rely on CISCRP to facilitate better communication and understanding between them, enhancing participant experience and trial outcomes.
- Participants are connected to policymakers since their experiences can inform regulatory changes. CISCRP plays a role in educating participants, who can then advocate for their own needs and contribute to shaping policy.
- CISCRP is connected to both groups: to pharmaceutical companies as a service provider and to participants as an educator and advocate, ensuring that the trials are understandable and accessible.

#### ***Critical Nature of These Groups:***

- Pharmaceutical companies are critical because they are the direct revenue source and the driving force behind clinical research innovation. Their needs dictate the market demand for CISC RP's services.
- Participants are critical because their willingness to join and stay in clinical trials is essential for the trials' success. Their diverse backgrounds necessitate a focus on DEI to ensure that clinical research is inclusive and equitable, which aligns with CISC RP's mission.
- Policymakers are critical as they can impose regulations that necessitate the services CISC RP provides, like plain language summaries. Positive participant experiences can lead to advocacy for more participant-friendly legislation, further entrenching the need for CISC RP's services.

These stakeholders form an ecosystem where CISC RP's services facilitate improved communication and understanding between pharmaceutical companies and participants, while also potentially influencing legislative changes that can impact the clinical research industry. Their interdependence means that growth in one area can stimulate growth in others, creating a cycle that drives CISC RP's long-term strategy. This information is summarized graphically in Figure 8 which represents the relationships between key players. Pharmaceutical companies are the most important stakeholders to success at CISC RP and should be managed closely, research participants should be kept informed as well as managed to a lesser degree, and legislative bodies should be kept satisfied.

## **Interviews**

Throughout the course of this project, our group conducted 7 interviews over Zoom, two were with leaders who had experience with DEI initiatives and 5 were with members of the CISC RP DEI council. Each interview was recorded and re-visited for the purposes of note taking and drawing

conclusions. Specific topics were classified on a per-interview basis as either “context”, “barriers”, or “strategies” to achieving progress towards DEI. The findings and key takeaways from these interviews are discussed and summarized below.

## ***DEI Leaders***

### ***Interview #1***

Our first interview was conducted with an individual who directed operational planning for a large healthcare system.<sup>22</sup> This person emphasized that the patient population served by their organization was mostly Latino, rural, and immigrant based.<sup>22</sup> These demographics were also mirrored in organizational leadership and were a reflection of the applicant pool in the local community rather than the result of intentional hiring efforts.<sup>22</sup> This was particularly true due to the local culture of retaining community members in positions of leadership and clinical experience.<sup>22</sup> This individual mentioned organizational barriers to implementing DEI programming, specifically with regard to black history month.<sup>22</sup> This person went on to explain how this barrier was largely related to confusion surrounding the necessity of DEI in the workplace as opposed to negative intentions.<sup>22</sup> Involving upper management was particularly valuable in overcoming this challenge and securing resources for DEI programming.<sup>22</sup> Furthermore, partnering with local community leaders like churches was valuable in terms of involving community members as key stakeholders.<sup>22</sup> Additionally, tracking metrics regarding DEI was a work in progress at the current organization but had been a point of strength at a previous position.<sup>22</sup> At this individual's previous position, metrics regarding DEI were tracked at the per-position level with a focus on diversifying the workforce and empowering candidates from diverse backgrounds to carry out research and patient care that supports these principles.<sup>22</sup> This interview concluded by discussing the importance of understanding why DEI is relevant to a specific organization, and which individuals are excluded from current policies.<sup>22</sup> DEI can mean something different for each organization and

hiring representatives of the communities served should be an important organizational priority.<sup>22</sup> However, this can be challenging for many reasons and if representation cannot be achieved, then cultural humility and the willingness to learn are essential to serve customers and patients.<sup>22</sup>

## ***Interview #2***

The second interview with a DEI leader was also conducted with an individual responsible for DEI at an institution affiliated with a medical center.<sup>23</sup> This individual cited strong organizational values interspersed in the hiring process as a successful strategy.<sup>23</sup> One limitation of this strategy is that it requires consistent reinforcement of these values and they must be supported throughout all aspects of the organization, not just in the hiring process.<sup>23</sup> Broadly, this individual mentioned cultural humility, competency, historical context, and political pushback as major barriers to furthering DEI initiatives across different organizations.<sup>23</sup> This individual suggested overcoming these barriers by framing DEI as health equity and quality/safety.<sup>23</sup> In this individual's current role, they have found leadership training and development focused on C-suite executives and front-line workers to be essential when implementing a culture that supports DEI.<sup>23</sup> Reinforcing a culture of DEI at the individual team level was an important message since this skill must be learned through training or mentorship.<sup>23</sup> Implementing monthly programming through a cultural calendar as well as panel discussions that celebrated and raised awareness of diverse cultures were strategies taken by this organization.<sup>23</sup> Monitoring KPIs regarding DEI was also a challenge for this organization due to limited data but was a future goal of theirs within the next few years with the potential to tie in performance reviews and incentives.<sup>23</sup>

## ***CISCRP Employee #1***

This interview with CISCRP staff revealed that the culture at CISCRP is friendly, collaborative, and adaptable.<sup>24</sup> This individual mentioned that the hybrid and remote work models have been effective in some instances and challenging in others.<sup>24</sup> This individual mentioned that everyone



at CISC RP benefits from working in an inclusive environment and that focusing on DEI is the right thing to do from both a moral and strategic perspective.<sup>24</sup> This individual mentioned the lack of any official internal policies with regards to DEI but mentioned the robust cultural competency exemplified by their product offerings.<sup>24</sup> One barrier this individual mentioned was with finding direction in DEI efforts and the pace of implementing them since everyone is well intentioned but may not have the experience to make progress.<sup>24</sup> This individual was optimistic about lunch & learns as well as the subject matter experts and consultants.<sup>24</sup> This individual mentioned that producing high quality DEI work takes time but that CISC RP has extensive support from leadership both in spirit and in resources.<sup>24</sup> This individual also mentioned a fellowship for underrepresented individuals in STEM that was modeled after government programs but had only been offered once so far.<sup>24</sup> One challenge of offering internships or low paying positions is that only individuals who could afford to participate would participate and that this inherently excludes some underrepresented individuals.<sup>24</sup> While this individual was hesitant about the feasibility of hiring someone dedicated to DEI due to the small organizational size, they were particularly receptive to the idea of monitoring progress towards DEI through KPIs.<sup>24</sup>

### ***CISC RP Employee #2***

This interview revealed that culture at CISC RP is positive and tightly knit with some individuals working remotely and some in-person.<sup>25</sup> To this individual, diversity meant ensuring representation of different people with different thoughts and experiences.<sup>25</sup> To this individual, equity meant equal access to resources and fairness in hiring.<sup>25</sup> To this individual, inclusion means ensuring that all perspectives are respected, particularly between in-person and remote employees.<sup>25</sup> This individual mentioned that every department interacts with DEI in some capacity at CISC RP but that no formal policies have been put in place yet.<sup>25</sup> This employee was optimistic about the ability of the consultant to guide change in the future through the development of the anti-bias toolkit and training.<sup>25</sup> One barrier this individual mentioned was that few employees had

previous experience in DEI and so the council had to rely on expert consultants.<sup>25</sup> One successful strategy that this employee described was the creation of a formal budget to “give teeth” to DEI initiatives.<sup>25</sup> Another barrier to DEI mentioned by this individual was the lack of feedback from CISCRP employees not on the DEI council after the initial lunch and learn and challenges in getting buy in when work for initiatives is done on an uncompensated/volunteer basis.<sup>25</sup> If this employee had unlimited resources, they mentioned that they would compensate people for their time on DEI efforts.<sup>25</sup> However, this individual mentioned that employing someone full time like a chief diversity officer would work in a larger company but would find challenges at CISCRP due to the smaller company size and more limited financial resources, possibly giving a full time role to something that might not be a full time project.<sup>25</sup>

### ***CISCRP Employee #3***

This individual mentioned that the importance of pursuing DEI initiatives at CISCRP stemmed from their previously mostly white employee population and lack of age diversity.<sup>26</sup> They mentioned that providing equal visibility and inclusion on committees is especially important.<sup>26</sup> One policy that this individual was aware of that supports DEI at CISCRP is the inclusion of statements in job applications that encourage candidates to apply regardless of whether they meet all criteria.<sup>26</sup> One key insight that this individual provided was that the hybrid staffing model can be a barrier to inclusion at CISCRP and that not all employees receive equal opportunities.<sup>26</sup> For example, individuals who work in-person may receive higher visibility from upper management and be given more opportunities to contribute accordingly.<sup>26</sup> This individual mentioned that a shift towards sending surveys more broadly may address this issue.<sup>26</sup> Anti-bias training in the hiring process was a strategy this individual believed would be effective in supporting DEI at CISCRP.<sup>26</sup> When interviewed about KPIs, this individual believed that this would be a good strategy to track progress towards DEI.<sup>26</sup> This individual advocated for hiring employees who could speak the languages of the communities they interact with.<sup>26</sup> Contrary to previous

interviews, this individual mentioned that it would be helpful to have a dedicated staff member who would focus on DEI at CISC RP.<sup>26</sup>

#### ***CISC RP Employee #4***

This individual provided key insights into barriers to progress in the DEI space within CISC RP.<sup>27</sup> This individual mentioned that there are some barriers to equal participation and hearing perspectives in certain initiatives, but that these are inherent to any organization.<sup>27</sup> Furthermore, this individual mentioned that this issue can be exacerbated when things need to be accomplished quickly and not everyone has had the opportunity to contribute their thoughts.<sup>27</sup> Another barrier this individual mentioned was that certain individuals on the committee had more power outside of the DEI council and it was difficult to separate these roles from power dynamics.<sup>27</sup> Because of this, this individual found value in a third party mediator and expressed interest in having a consultant.<sup>27</sup> This individual also mentioned the same barriers mentioned by employee #3, that certain individuals are chosen for certain positions based on their reputation or relationships with other employees.<sup>27</sup> This individual was passionate about the importance of DEI initiatives at CISC RP and wanted standardized guidelines so that managers could know what they can do to create a culture of DEI within their teams.<sup>27</sup>

#### ***CISC RP Employee #5***

This interview revealed that the culture at CISC RP is very open and inviting.<sup>28</sup> Similar to previous interviews, this conversation mentioned that the company was initially very homogenous in appearance but that progress has been made in this aspect.<sup>28</sup> Furthermore, this interview reinforced how everyone benefits from DEI at CISC RP and that it can shed light on new perspectives for projects and meetings.<sup>28</sup> This individual mentioned that CISC RP's recent DEI statement and its policies conforming to regulations about disabilities are examples of progress in the DEI space.<sup>28</sup> While this individual mentioned that there are no current metrics tracked with

regards to DEI, senior leadership is very involved in the process and committed to longitudinal change.<sup>28</sup>

## ***Key Themes***

### ***DEI Leaders***

Both DEI leaders worked for similar organizations, large medical centers that placed an emphasis on how DEI impacts their employees and their patients.<sup>22-23</sup> Additionally, both leaders mentioned barriers in understanding the importance of DEI strategy both internally and externally.<sup>22-23</sup> A common theme among both interviews was the importance of measuring progress towards DEI and getting buy-in from the community.<sup>22-23</sup> To best serve diverse patients, staff should represent the people they work for and if they cannot, they should strive to learn cultural competence and humility.<sup>22</sup> Both of these interviews also touched on the importance of not only support for DEI from management, but specific training targeted towards leaders that empower them to cultivate a culture of DEI.<sup>22-23</sup>

### ***CISCRP Employees***

Common themes from CISCRP employees included the positive culture at CISCRP and the willingness to learn together.<sup>24-26,28</sup> Additionally, many employees mentioned the positive buy-in from leadership and contribution of financial resources as strong assets.<sup>24,25,28</sup> However, employees also noted barriers to inclusion including preference to the perspectives of in-person employees, the slow pace of progress, and the limitations due to small organizational size.<sup>24-27</sup> Several employees also discussed the need for established guidelines regarding DEI and an interest in formally tracking KPIs.<sup>24,26,27</sup>

## ***Synthesis***

DEI is important from both moral and strategic standpoints.<sup>8,24-28</sup> After reviewing literature on guidelines regarding successful implementation of DEI strategy, it is evident that the first step is identifying the importance and relevance of DEI to a specific organization.<sup>6,8,9,22,23</sup> Subsequently, it is important to identify which individuals are left out of policies, what barriers exist to furthering DEI, and what steps can be taken to overcome them.<sup>6,8,9,22,23</sup> Through a combination of literature review and stakeholder interviews, we identified common challenges when addressing DEI to include lack of organizational focus, misconceptions about the need for DEI, inadequate financial support, and under-commitment to longitudinal change among others.<sup>6,8,9,24-28</sup> Many companies have found success in achieving DEI through a variety of practices like training, leadership development, raising cultural awareness, hiring pipelines, revision of existing policies, partnerships with community leaders, and creating positions dedicated to DEI.<sup>6,8,9,22,23</sup> However, not all of these strategies can work for every organization. One key theme that persisted across literature review and interviews was the need for, and utility of, formal KPI tracking related to DEI.<sup>7,22,23</sup> Several examples of KPIs from literature review involve monitoring performance review, the number of applicants leaving a position, and the rates of promotion through a DEI lens.<sup>7</sup> Interviews revealed that formal monitoring of KPIs are currently done at some large organizations and would be desirable to CISCRP employees.<sup>22-28</sup> When comparing current practices at CISCRP with the internal DEI strategies taken by other organizations, as demonstrated in Figures 7 and 9, it is clear that they have already created a strong foundation by engaging upper management and securing financial support.<sup>24-28</sup> Furthermore, CISCRP's current work with a DEI consultant to create training programs and lunch & learns will be helpful in raising awareness of DEI.<sup>24-28</sup> However, CISCRP's greatest asset in achieving progress towards DEI principles is their willingness to learn and keep an open mind with regard to new perspectives. Conversations with current employees revealed that some perspectives may be underutilized, and involving the greater CISCRP workforce outside of the DEI council could prove to be beneficial.<sup>24-28</sup> Strategic

alternatives to address these barriers with our final recommendations are presented in subsequent sections.

### **Strategic Alternatives**

Based on the data we collected, we have identified seven strategic alternatives CISC RP can explore with the goal of bolstering internal DEI initiatives. The alternatives/options have been judged based on three criteria: the time frame of impact, cost/resources required, and hypothetical outcome/impact. Based on these criteria, the strategic alternatives were judged and ranked from most impactful to least impactful to internal DEI initiatives at CISC RP.

#### **1. Engage the Whole Organization in DEI Efforts**

Currently, internal DEI initiatives employ a top-down model, where decisions and conversations are mainly conducted by upper management and company leaders.<sup>24-28</sup> Among the information gathered from company surveys and interviews, one of the issues surrounding internal DEI stems from not gauging the interest and ideas of everyone in the organization.<sup>24-28</sup> By having the whole workforce be involved in the DEI efforts, it creates individual responsibility to advancing DEI efforts across the organization. Challenges due to the number of hybrid and remote workers at CISC RP can be a hindrance to this effort.<sup>24-28</sup> However, we believe through regular workshops, such as the lunch and learns, feedback sessions, and inclusive decision making processes, CISC RP can gather the differing perspectives of its employees to make meaningful change. Although in the short term, the involvement of everyone might cause more problems pertaining to the direction of internal DEI initiatives, we feel it is a necessary step for the company to truly be inclusive in the long term. Throughout our research and interviews with other organizations, a theme of DEI policies being a representation of the community being served and the staff at the organization was prevalent.<sup>22</sup> By engaging not only the individuals serving on the DEI counsel, but everyone

in the organization, it ensures the inclusion of different perspectives and empowers employees to take an active role in advancing internal DEI efforts.

## **2. Formal Monitoring Process of KPIs**

Implementing a formal monitoring process for DEI-related KPIs, developing a DEI scorecard, and incentivizing DEI milestones collectively create a robust framework for fostering and evaluating diversity, equity, and inclusion at CISC RP. By formalizing the monitoring of KPIs, such as employee retention and hiring rates from diverse backgrounds, CISC RP can objectively assess the effectiveness of its DEI initiatives, ensuring that efforts are data-driven and results-oriented.<sup>7</sup> The DEI scorecard further complements this by providing a regular assessment across various DEI parameters, including employee sentiment and leadership diversity. This holistic view enables the organization to make informed decisions and adapt strategies responsively. Additionally, incentivizing DEI milestones through recognition and bonuses serves to embed DEI deeply within the corporate culture, motivating employees to actively participate in and prioritize DEI efforts. This strategic combination not only boosts morale but also aligns employee goals with organizational DEI objectives, enhancing overall engagement and commitment.

However, these strategies also introduce several challenges. The formal monitoring of KPIs and the maintenance of a DEI scorecard require significant resource investment in terms of technology, training, and potentially new hires to manage these systems. This could strain budgets and divert funds from other critical areas. There is also the risk of focusing too narrowly on quantitative measures, which might neglect the nuanced, qualitative aspects of workplace diversity and inclusion that are harder to capture with metrics. Moreover, while incentives can drive engagement, they might also lead to competitiveness or gaming the system, where employees focus more on meeting the criteria for rewards rather than genuinely engaging with the spirit of DEI initiatives. Misalignment between the intention of the incentives and actual

outcomes could potentially undermine the authenticity of DEI efforts and create rifts within the workforce.

### **Strategic Prioritization:**

In prioritizing these strategic alternatives, CISCRP should consider the direct and indirect impacts on both the organizational culture and operational effectiveness. The key criteria for prioritization include:

- **Impact and Sustainability:** Strategies that offer long-term benefits and have the potential to create a sustainable positive impact on the organizational culture should be prioritized. The DEI scorecard, which provides ongoing feedback and visibility into DEI efforts, scores highly on this criterion.
- **Resource Efficiency:** Considering the resource intensity of these strategies, prioritizing those that require minimal ongoing operational costs while still delivering significant value is crucial. In this regard, incentivizing DEI milestones might be more resource-efficient compared to the continuous data management needs of KPI monitoring and scorecard maintenance.
- **Alignment with Organizational Values and Goals:** Strategies that closely align with CISCRP's core values and broader organizational goals should be prioritized. All three strategies align well, but formal KPI monitoring stands out as it directly measures the effectiveness of DEI initiatives, providing crucial data to inform strategic decisions and adapt policies.

By focusing on strategies that are sustainable, resource-efficient, and closely aligned with organizational values, CISCRP can effectively enhance its DEI initiatives, creating a more inclusive and equitable work environment.

### **3. Expand and Standardize DEI Training**



The expansion of DEI training initiatives across CISC RP offers a multitude of advantages. Firstly, it promises to enhance cultural competency among all employees. Such a program equips the workforce with critical skills necessary to navigate and respect the diversity intrinsic to a globalized work environment. Additionally, the focus on leadership and management training ensures that DEI principles are not only implemented but also modeled from the top, thereby potentially fostering a trickle-down effect that could permeate the entire organizational structure. This could lead to a more inclusive and understanding leadership approach, promoting a positive, comprehensive cultural shift within CISC RP. Standardization of these training efforts means a cohesive message and set of practices would be disseminated, minimizing inconsistencies and aligning everyone with the organization's DEI objectives. Moreover, integrating DEI initiatives into the fabric of everyday tasks ensures that the principles of diversity, equity, and inclusion become a regular part of the operational workflow, reinforcing their importance and normalizing their presence in all business processes.

However, there are considerable challenges to the implementation of such a program. Resource allocation stands as the foremost concern; a comprehensive DEI training scheme can be costly and time-consuming, diverting staff from their usual duties and potentially impacting productivity. The effectiveness of the training is also a concern—ensuring the programs genuinely engage employees and lead to substantive change in behavior rather than merely serving as a perfunctory activity is a nontrivial challenge. Beyond the initial implementation, the organization must commit to maintaining and updating the program, which involves continuous investment. DEI concepts and societal norms evolve, necessitating regular program refreshes to stay current and effective, which would add to the sustained operational costs.

**Strategic Prioritization:**

- **Impact on Organizational Culture:** The potential to create a deep and lasting impact on the organization's culture through DEI training is significant. Employees at all levels would be empowered with the knowledge and skills to contribute to a more inclusive workplace.
- **Cost vs. Benefit:** While there is a considerable cost attached to the development and execution of DEI training, the benefit of a more competent and inclusive workforce may justify the expenditure.
- **Alignment with CISC RP's Mission:** As an organization that values education, the expansion of DEI training aligns closely with CISC RP's core values and enhances its credibility in the space of patient outreach and education.

Expanding and standardizing DEI training at CISC RP involves creating a structured program that would comprehensively cover DEI topics relevant to the organization's mission and workforce. Such a program would require ongoing investment but would offer the benefit of a consistently informed and culturally competent staff. The decision to implement this strategic alternative would need to weigh the immediate resource requirements against the long-term cultural and operational benefits.

#### **4. Culture and Heritage Monthly Programing**

Aside from offering education and training for staff, celebrating religious holidays, events and holidays that celebrate gender and racial inclusivity as well as historical events are a great way to increase visibility of different cultures and groups.<sup>23</sup> These can be events that celebrate the culture or just information being provided on the company website or work-related forum channels such as Slack. This is something that CISC RP can implement with little cost and resources while being able to build internal traditions and celebrate diversity. This will have a noticeable impact almost immediately, with more people exposed to different cultural holidays as well as being more connected to those around them. This, however, needs to be done with extensive research and

cultural humility, there is a fine line between cultural celebration and cultural appropriation. Therefore, long term impact will depend on employee perception, which is hard to predict and measure, thus making this an alternative strategy and not a recommendation.

## **5. Hiring of Full-time Employee for DEI**

One of the main barriers to the success and implementation of DEI initiatives at CISCPR is a lack of direction with best practices surrounding DEI. Although bringing on a consultant to help with the direction of current DEI initiatives is helpful in the short-term, hiring someone full time that is spearheading the DEI initiative can help with direction and consolidate ideas that members of the existing counsel have, leading towards a more unified and cohesive approach. In the short-term, it sends a strong message to employees and external stakeholders about the company's commitment to improving internal DEI. Long term, a full-time staff focusing on DEI can ensure the continuous improvement of DEI initiatives and further the organization's mission. However, hiring someone to focus solely on DEI is costly, not just with the person's salary, but also benefits and additional unforeseen costs such as training and resources the individual may require.<sup>24-28</sup>

## **6. Recruitment Programs: Internship/Fellowship**

CISCPR has already had a pilot in this program.<sup>24</sup> However, expansion of this program could lead to further advancements in staff diversity and companywide equity. A possible avenue of expansion is the creation of a mentorship program for underrepresented groups. The mentorship program creates an opportunity for CISCPR to examine barriers that currently exist for certain demographics and target DEI policies towards addressing those barriers. This is a costly endeavor, especially due to the nature of CISCPR as a small, non-profit organization. Funding will need to be secured with no promise of expanding DEI internally. However, this is one way of reaching communities that CISCPR serves and will further CISCPR's community outreach

initiatives, increasing DEI externally with their products and services, and a possibility of increasing the diversity of the workforce at CISC RP internally in the long term.

## **7. Formal Grants and Equity-focused Research Initiatives**

Implementing formal grants to support innovative DEI projects proposed by employees, alongside equity-focused research initiatives, serves to deeply integrate DEI into the fabric of CISC RP. These strategies collectively empower employees to lead and participate in DEI development actively, fostering a strong sense of ownership and engagement across the organization. This bottom-up approach from the grant programs encourages creativity and innovation in DEI efforts, ensuring the solutions are directly relevant to the needs identified by employees themselves. On the other hand, equity-focused research initiatives position CISC RP at the forefront of DEI leadership, contributing to the broader discourse and potentially setting new standards within the industry. These research projects can yield actionable insights that improve internal policies and practices while enhancing CISC RP's credibility and influence in promoting equity.

While both strategies are ambitious, they come with significant administrative and financial burdens. Managing a grant program internally requires rigorous oversight, including the setup of processes for application, review, and funding distribution, which can be resource intensive. There's also the inherent challenge of ensuring these initiatives lead to tangible outcomes, with the risk that the projects may not achieve the expected impact, potentially affecting the justification for continued investment. Similarly, equity-focused research initiatives demand substantial upfront investment and sustained commitment, which may divert resources from other critical areas. The uncertainty of research outcomes and the complexity of managing collaborations with external entities can further complicate execution and effectiveness.

### **Strategic Prioritization:**

When prioritizing these initiatives, CISC RP should consider their alignment with long-term organizational goals and their potential to make substantive improvements in DEI. The grant program, by enabling direct employee involvement in DEI efforts, not only enhances engagement but also ensures that initiatives are grounded in real-world experiences and needs. This could lead to high-impact outcomes that resonate across the organization. Equity-focused research, while more speculative, could yield significant long-term benefits by establishing CISC RP as a leader in DEI best practices. The choice between these initiatives should weigh the immediate benefits of employee engagement and innovation against the broader, potentially transformative impacts of pioneering research in equity.

### **Strategic Recommendations**

Our strategic recommendations for CISC RP are centered around fostering a more inclusive workplace environment, integrating diversity, equity, and inclusion (DEI) initiatives into everyday operations, and prioritizing employee involvement and training. Listed below is a narrative review of the proposed strategic recommendations:

CISC RP faces the challenge of navigating through its hybrid and virtual work setting while striving to build an inclusive culture that values diversity in all its forms.<sup>24-28</sup> With insights gleaned from various perspectives within the organization, it's evident that there's a collective willingness to learn and improve, but the lack of structured initiatives and resources poses a barrier to progress.<sup>24-28</sup> To address these challenges, we recommend prioritizing strategic alternatives that align with CISC RP's mission, resources, and timeframe for impact.

**1. Engage the Whole Organization in DEI Efforts, particularly remote employees and employees outside of the DEI council:** Creating opportunities for all employees to contribute to DEI discussions and decisions, not just those on the DEI committee, is crucial for fostering a sense of ownership and collective responsibility towards DEI goals. We believe that by facilitating

regular workshops, feedback sessions, and inclusive decision-making processes, CISC RP can harness the diverse perspectives and talents of its workforce to drive meaningful change. Also, given the unique hybrid and virtual work settings at CISC RP, it's imperative to create initiatives that specifically address inclusivity in a digital context. Virtual team-building activities and the promotion of remote work advocates can significantly enhance the sense of belonging and inclusion. This recommendation aligns with the insights provided by CISC RP employees, who highlighted the challenges of virtual communication and the importance of creating an inclusive environment for all, regardless of the work format.<sup>24-28</sup> Additionally, involving individuals outside the DEI committee ensures diverse perspectives are considered and empowers all employees to play a role in driving change.

**2. Develop a DEI Scorecard/dashboard:** Employing quantitative methods to assess DEI initiatives at CISC RP will allow them to maximize their impact and follow best practices. It is for this reason that we recommend a formal monitoring process for key performance indicators (KPIs) through a DEI scorecard or digital dashboard related to diversity, equity, and inclusion. This dashboard can monitor KPIs such as employee retention, promotion rates, and performance reviews with a focus on DEI.<sup>7</sup> We believe that a dashboard could provide valuable insights, transparency, accountability, and could track progress over time. This recommendation aligns with the need highlighted by several employees for measurable outcomes.<sup>24-28</sup>

CISC RP can also gather feedback on employee sentiment through surveys, feedback sessions, and other channels. Additional components of this recommendation are discussed below.

- **Incentivize DEI Milestones:** By recognizing and celebrating contributions to DEI, CISC RP can motivate employees to actively engage in DEI initiatives and integrate DEI principles into their daily work. This was a common theme in our interviews with DEI leaders and emphasized the importance of buy-in from leadership and community

partners.<sup>22-23</sup> Integrating DEI considerations into corporate policies and practices, such as recruitment, performance reviews, and incentive programs, is another key recommendation for implementing and executing DEI practices.<sup>23</sup> This ensures that DEI is embedded into the fabric of the organization and is not treated as a separate or optional initiative.<sup>22-23</sup>

### **3. Expand and Standardize DEI Training, specifically with leadership and skill development**

**for diverse employees:** Expanding and standardizing DEI training programs for all employees, including leadership and management, is essential to ensure that DEI values are integrated into everyday tasks and decision-making processes. However, it is important to recognize that DEI initiatives that focus on changing people's perspectives can be short lived.<sup>29</sup> To combat this, we recommend CISC RP to continue with its anti-bias trainings and consider cultural competency trainings, but also to include trainings that focus on leadership development, and skill building, available to all but particularly for diverse individuals.<sup>29</sup> Furthermore, training on how to identify which policies unconsciously place certain groups at a disadvantage, should be provided in conjunction with the DEI scorecard to measure results. This initiative requires moderate resources but can yield substantial benefits in terms of fostering a culture of inclusivity, increasing cultural competency among employees, and mitigating biases in hiring and decision-making processes. Furthermore expanding trainings from both the perspectives of cultural competency and bias in addition to process evaluation and professional development, with a focus on diverse individuals, can be very beneficial at CISC RP.<sup>29</sup> CISC RP currently has a strong culture of willingness to learn and this will serve them well in their ability to broaden their cultural perspectives and support existing employees.

- **Culture and Heritage Monthly Programming:** To enhance the organizational culture and promote cultural awareness in a vibrant manner, we recommend implementing monthly programming to celebrate cultural holidays.<sup>23</sup>

We decided to prioritize the recommendations above based on their estimated cost-benefit analysis, long-term and short-term impacts, and hypothetical outcomes. We prioritized engaging the entire organization in DEI efforts as our first recommendation since it is the least costly and most potentially beneficial option to exploring diverse perspectives within CISC RP. We prioritized developing a DEI scorecard and utilizing KPIs as our second recommendation because we believe it is a valuable tool for measuring DEI initiatives from a quantitative perspective, received positive feedback from CISC RP employees, and was mentioned by both DEI leaders.<sup>22-28</sup> This recommendation is particularly valuable for its ability to monitor and measure the success of DEI programs.<sup>22</sup> We prioritized establishing robust training programs for leadership development and cultural awareness as our third recommendation since it provides a valuable tool for developing DEI culture at multiple levels and already has significant buy-in from CISC RP employees.<sup>22-28</sup>

Understanding and implementing DEI initiatives within the organization is the first step towards making meaningful changes in the broader community. However, challenges such as resistance to change, resource constraints, and the need for ongoing evaluation and adaptation may arise. Therefore, it's crucial for CISC RP to remain agile, proactive, and committed to its DEI goals in order to achieve sustainable progress and impact. It's important to recognize that these changes may take time to fully materialize, requiring ongoing dedication, resources, and support from leadership and stakeholders throughout the organization.

If these recommendations are fully implemented, we expect that CISC RP will see a more inclusive, equitable and engaged workforce, improved diversity in leadership roles, enhanced employee satisfaction and retention, improved collaboration and innovation, strengthened relationships with diverse communities, and ultimately, greater organizational success and impact in advancing health communication services.

### **Implementation Plan**



Described below are the timeframes, suggested steps for implementation, and short term/long term goals for each of the recommendations described above.

**Recommendation #1: Engage the Whole Organization in DEI Efforts**

*Short term goal:* Increase involvement of employees not on the DEI council, in DEI initiatives

- 1-2 months
  - Create dedicated tools to collect staff feedback on DEI efforts.
  - Consider implementing breakout groups during lunch & learns which would be facilitated by members of the DEI council.
  - Send anonymous surveys to remote employees to gauge how they feel their perspectives are valued during decision making.

*Long term goal:* Increase representation of remote employees in DEI roles and value of their perspectives.

- 2+ month
  - Identify strategies that support the perspectives of remote workers based on feedback from surveys.
  - Engage leaders from each department to understand the needs of their remote and in-person workers.

**Recommendation #2: Develop a DEI Scorecard**

*Short term goal:* Determine which KPIs can be feasibly collected and at what rate.

- 1-2 months
  - Identify which KPIs are already being collected through surveys and which are most useful to the organization.

- Examples include: rates of hiring, attrition, promotion, and feelings of inclusion through surveys.<sup>7,30-31</sup> Due to the smaller organizational size and information gained in our interviews, focusing on feelings of inclusion through surveys may be most relevant unless during times of turnover and promotion.
- 2-6 months
  - Monitor the collection of these KPIs over time.

*Long term goal:* Track progress towards meeting CISCPR's DEI goals over time using the DEI scorecard.

- 1+ year
  - Consider incentives related to DEI and inclusivity of perspectives in performance review if applicable.
  - Leverage performance reviews as an opportunity to collect feedback on DEI efforts.
  - Work with Human Resources to update and store data on KPIs over time.

**Recommendation #3:** Expand and Standardize DEI Training, particularly with a focus on leadership, skill development, and policy review.

*Short term goal:* Implement monthly cultural programming on a small scale and skill development for employees with a focus on cultural humility and competency.

- 1-2 months
  - Identify which cultural programming is relevant based on holidays and time of year.<sup>32-33</sup>

- Identify individuals to lead cultural programming efforts, these individuals do not need to be from the background being highlighted but could consult with individuals from this culture. These individuals do not need to be CISC RP employees.
- Implement organizational wide cultural humility and competency training. (Example Topics: Reducing Prejudice, Stereotyping, Unconscious and Implicit bias, Addressing microaggressions etc.)
- Identify which types of skill-based training are most relevant and of interest to CISC RP employees, possibly through surveys.

*Long term goal:* Create a more diverse, equitable, and inclusive workplace culture at CISC RP by empowering leaders, reviewing policies, and developing stronger teams.

- 6+ months
  - Establish leadership training on how to build DEI culture in their specific team.
    - Provide managers with structured guidelines to accomplish this, possibly with the use of the DEI consultant.
  - Establish leadership pipelines as applicable that prepare diverse candidates to take leadership roles.
  - Provide skill development workshops relevant to individual positions.
  - Train leaders and managers to review policies in their departments and identify which groups are left out, pair this with the use of the DEI scorecard for quantitative data.

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## **Appendix**

<b><u>Products &amp; Services</u></b>	<b><u>Summary</u></b>
<b>Health Communication</b>	<ul style="list-style-type: none"><li>• Translating scientific documents into everyday language (7th grade level)</li><li>• Assisting with trial participant communication</li><li>• Hosting health literacy workshops</li><li>• Health communication focused web content</li></ul>
<b>Scientific Research</b>	<ul style="list-style-type: none"><li>• Patient and care advisory board</li><li>• Market research in clinical trials</li><li>• Clinical trial journey workshop</li></ul>
<b>Content Licensing</b>	<ul style="list-style-type: none"><li>• Creating content centered around health literacy in the form of videos, brochures, infographics, and videos for companies to license</li><li>• Create content for companies that contract their services</li><li>• Focusing on diversity and inclusion in scientific research</li></ul>
<b>Events</b>	<ul style="list-style-type: none"><li>• AWARE for All</li><li>• Journey to better Health</li></ul>

**Figure 1:** CISCRP products separated by category.

<b><u>Research Services</u></b>	<b><u>Health Communication Services</u></b>
<ul style="list-style-type: none"> <li>• Savvy</li> <li>• Reverba</li> <li>• CorEvitas (formerly known as HealthiVibe)</li> <li>• Langland</li> <li>• Legacy Health Strategies</li> <li>• Lumanity</li> <li>• VOZ Advisors</li> <li>• Self-Care Catalysts</li> <li>• Origins Insights</li> </ul>	<ul style="list-style-type: none"> <li>• Health Literacy Media</li> <li>• TrialScope</li> <li>• MMS Holdings</li> <li>• Syneos Health (which acquired Kinapse)</li> <li>• Kateric</li> <li>• Companies specialized in Medical Writing, such as OPG and BOLD Science</li> <li>• Contract Research Organizations (CROs) e.g MEDPACE</li> </ul>

**Figure 2:** CISCRP Competitors separated by product category.



Figure 3: CISCRP's mobile exhibit.<sup>7</sup>







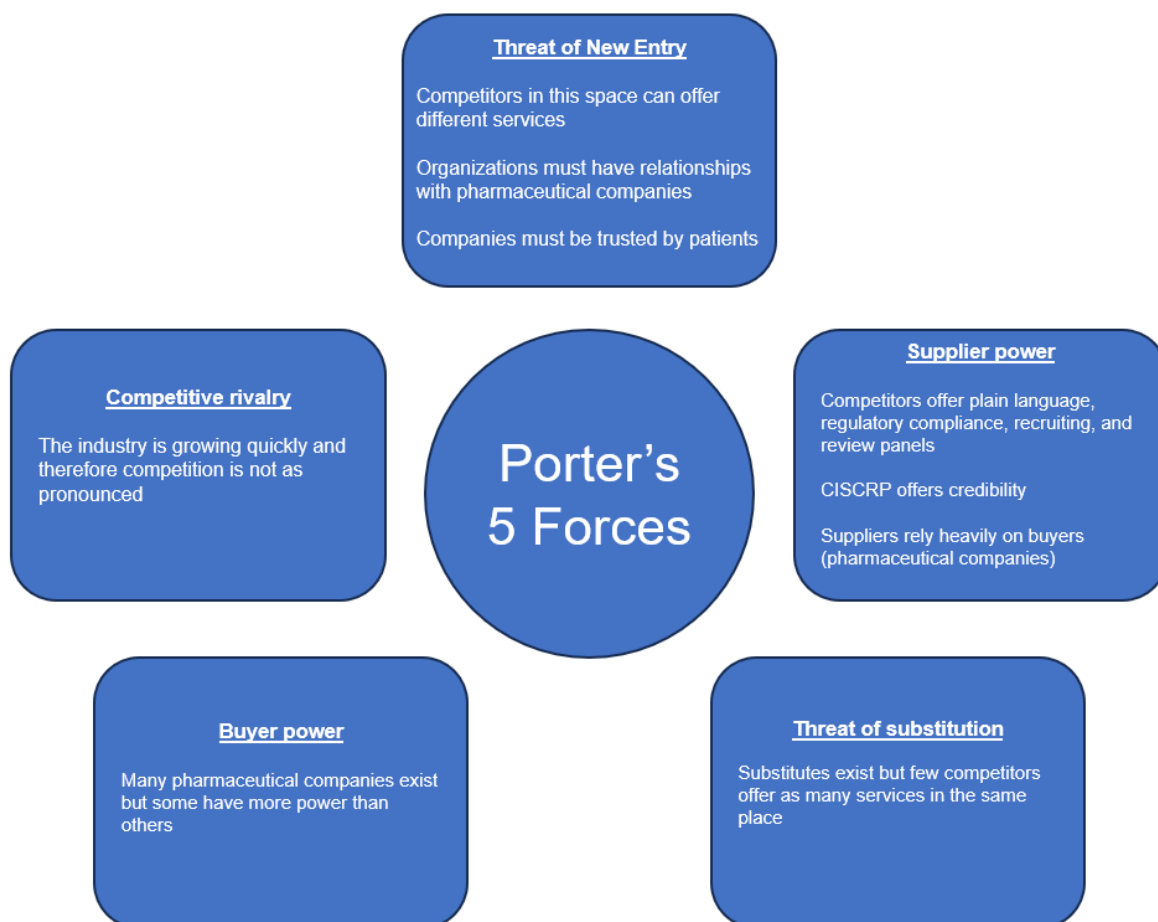
						
Plain Language Services	✓	✗	✗	✓	✗	✗
Content Licensing	✓	✓	✗	✓	✗	✗
Advisory Boards	✓	✗	✓	✗	✓	✓
Functional Databases	✓	✓	✓	✗	✗	✗
App Integration	✗	✓	✗	✗	✗	✗
Regulation Compliance	✓	✓	✓	✗	✗	✓
Community Engagement	✓	✓	✗	✗	✓	✗
Strategic Consulting	✗	✓	✓	✗	✓	✓
Diversity Focus	✓	✓	✗	✗	✓	✗
Professional Trainings	✗	✓	✓	✓	✗	✗

Figure 4: Competitor analysis based on products offered.



<b>Strengths</b> <ul style="list-style-type: none"> <li>• Plain language summaries</li> <li>• Review Panels</li> <li>• External DEI Focus</li> <li>• Direct community engagement</li> <li>• Culturally competent materials</li> </ul>	<b>Opportunities</b> <ul style="list-style-type: none"> <li>• Changing legislation in Europe requiring plain language</li> <li>• Changing legislation in the United States requiring outreach to diverse participants</li> <li>• Clinical trial market growth since pandemic</li> </ul>
<b>Weaknesses</b> <ul style="list-style-type: none"> <li>• Internal DEI environment</li> <li>• Smaller organization than similar competitors</li> </ul>	<b>Threats</b> <ul style="list-style-type: none"> <li>• Cultural beliefs towards transparency in research in other countries</li> <li>• Technological integration from competitors</li> </ul>

**Figure 5:** CISCRP SWOT Analysis.

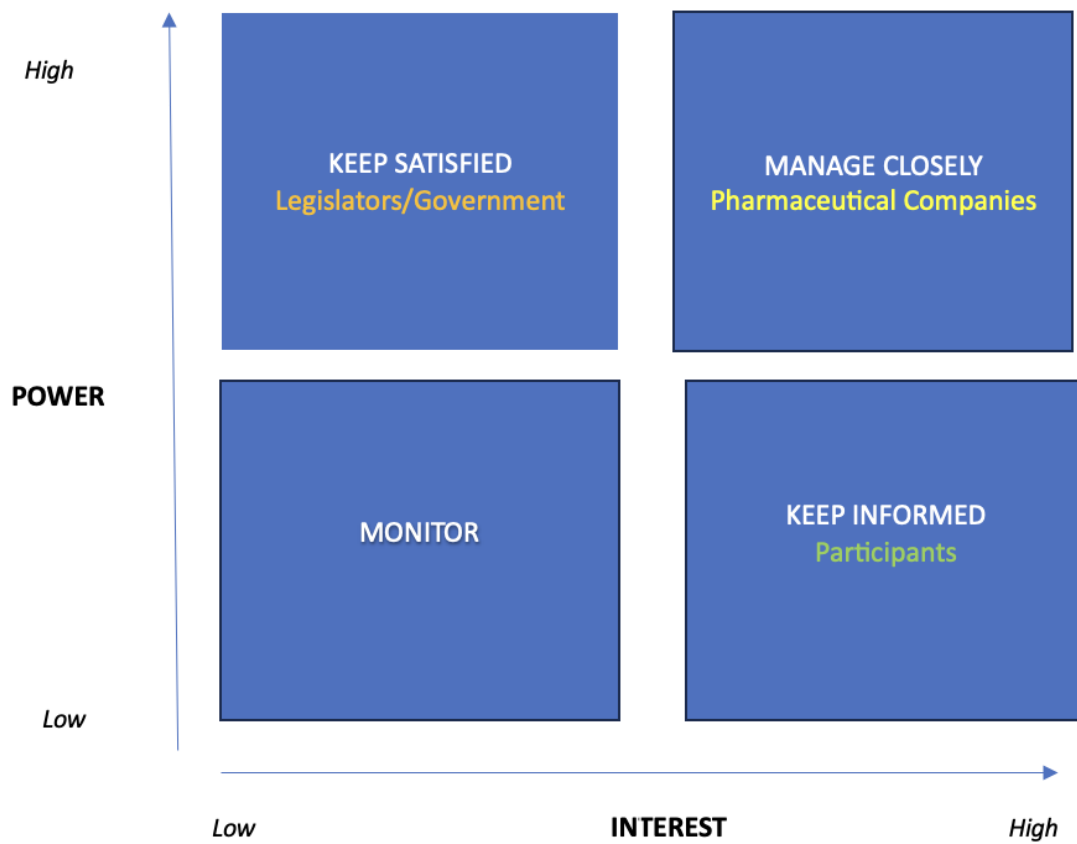


**Figure 6:** CISCRP Porter's 5 Forces.

<b><u>Company</u></b>	<b><u>Internal DEI Strategy</u></b>	<b><u>External DEI Strategy</u></b>
Savvy	-	Recruiting diverse patients for DEI council
Reverba	-	Emphasis on recruiting diverse patients
CorEvitas	Value Diversity	-
Langland	-	Head of diversity Initiatives in clinical trials
Legacy Health Strategies	-	Emphasis on recruiting diverse patients
Lumany	Enrichment programs, leadership, formal opportunities, community relationships	-
VOZ Advisors	-	Emphasis on recruiting diverse patients
Self-Care Catalysts	-	-
Origins Insights	-	-
Health Literacy Media	DEI Manager, training, recruitment, retention	-
MMS Holdings	Diversity statement, management across regions, global talent competition, bias workshops	-
Syneos Health	DEI council and statement	DEI consulting focus
ProPharma	DEI program leader, DEI committee, Newsletters/Lunch&Learns/Trainings	-
MEDPACE	-	Focus on recruiting diverse patients, training, diverse site selection, education, culturally relevant materials
- : None listed on website		

**Figure 7:** Competitor analysis by Internal and External DEI strategies.

## THE POWER - INTEREST MATRIX

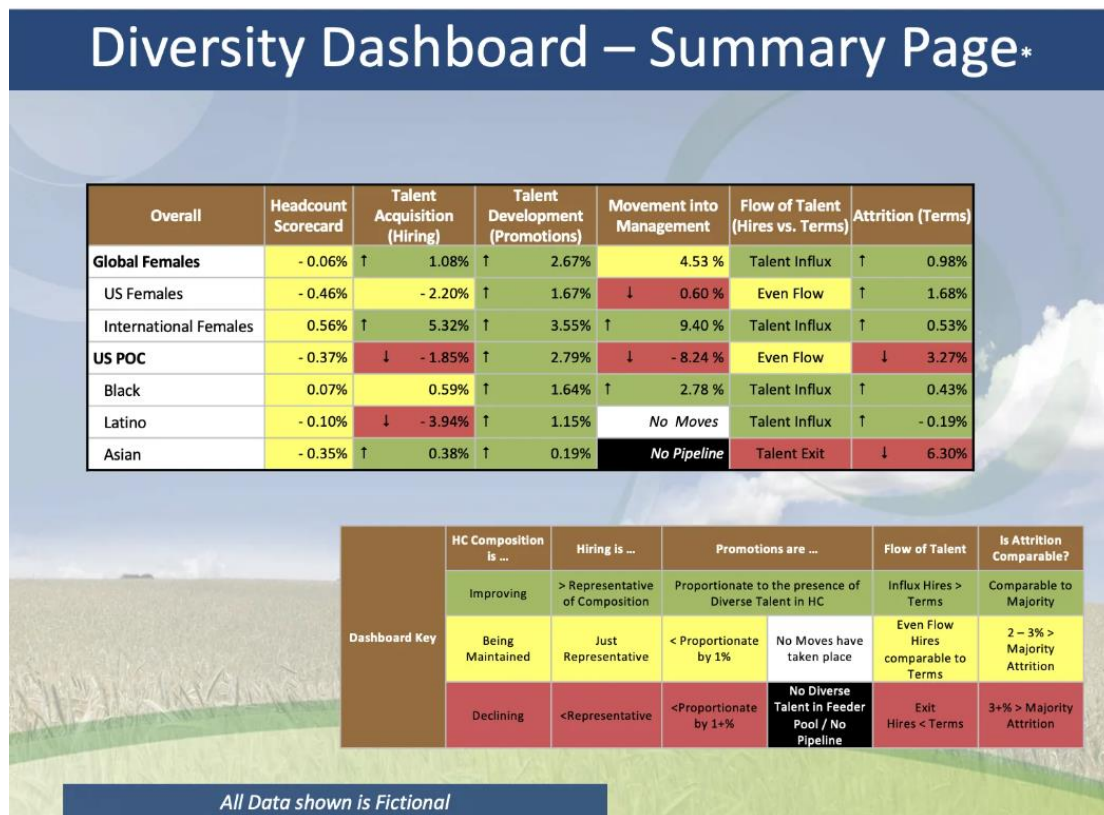


**Figure 8:** Stakeholder Analysis.

<b>Internal DEI Practices</b>	<b>CISCRP</b>
Relevant Mission	Yes
Trainings	In progress
Leadership Development	Not at this time
Representation	In progress
Cultural Awareness Programming	Not at this time
Hiring Pipelines	In progress
Partnerships with Community Organizations	Yes
Revision of Existing Policies	In progress
Formal Monitoring of KPIs	Not at this time
Support of Upper Management	Yes
Dedicated Financial Resources	Yes
Longitudinal Commitment	Yes
Dedicated DEI Position	Not at this time

**Figure 9:** Comparison of valuable internal DEI practices with current CISCRP efforts

## Gender Diversity Metrics Scorecard with Hires and Turnover



Figures 10: Sample DEI Scorecard/Dashboards.<sup>30-31</sup>

2024



# Harvard Heritage and Awareness Calendar

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<b>JANUARY</b> 1/15: Martin Luther King Jr. Day	<b>FEBRUARY</b> <b>Black History Month</b> 2/4: Rosa Parks Day 2/10: Lunar New Year 2/24: Lantern Festival	<b>MARCH</b> <b>Women's History Month</b> 3/8: International Women's Day 3/31: International Transgender Day of Visibility
<b>APRIL</b>  Sexual Assault Awareness Month  Arab American Heritage Month	<b>MAY</b>  Asian American & Pacific Islander Heritage Month  Mental Health Awareness Month Jewish American Heritage Month 5/6: Holocaust Memorial Day - Yom HaShoah	<b>JUNE</b> <b>LGBTQ+ Pride Month</b>  6/19: Juneteenth
<b>JULY</b>  Disability Pride Month	<b>SEPTEMBER</b>  Latinx Heritage Month	<b>OCTOBER</b> <b>LGBTQ+ History Month</b> <b>National Disability Employment Awareness Month</b> 10/14: Indigenous Peoples' Day 10/11: National Coming Out Day
<b>NOVEMBER</b> <b>Native American Heritage Month</b> 11/8: National First Generation Day 11/20: Transgender Day of Remembrance	<b>DECEMBER</b> 12/3: International Day of Persons with Disabilities	Use this calendar to plan inclusion efforts and submit events to: <a href="https://edib.harvard.edu/calendar-submissions">edib.harvard.edu/calendar-submissions</a>

Consider religious observances in event planning with Harvard Divinity School's Multifaith Calendar: [bit.ly/HU-multifaith](https://bit.ly/HU-multifaith)

Figure 11: Sample Cultural Calendar.<sup>32-33</sup>