CLL Society

Diversity, Equity, and Inclusion
Strategy Report

Indiana University

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Table of Contents

Executive Summary

The CLL Society is a patient–centric, physician–curated nonprofit organization focused on patient education, support, and research. Dedicated to addressing the unmet needs of the chronic lymphocytic leukemia (CLL) community, they explain the evolving therapeutic landscape, promote the importance of clinical trials, support and build patient networks, engage in research, and educate providers and patients.

Numerous studies have highlighted the disparities that exist in healthcare delivered to minority populations in our country. To achieve optimal health in our society we must address biases and other barriers that prevent us from accessing and serving diverse populations.

CLL Society is seeking a diversity, equity, and inclusion (DEI) plan; a way to integrate it into strategic decisions and operational priorities. The following tasks were completed by Indiana University graduate student participants in the O'Neill School of Public and Environmental Affairs Capstone to assist the CLL Society to move forward in developing a strategic and operational DEI plan.

Literature Review

The Literature Review team reviewed academic and medical literature concerning disparities within cancer, CLL, and clinical trials. Literature Review team members conducted research independently before convening to combine the resulting sections of the literature review. The literature review section is descriptive in nature and therefore does not propose any recommended actions for CLL Society to consider. The general research and writing process is outlined below.

- Conducted research and summarized relevant articles.
- Organized information into separate outlines.
- Composed rough drafts.
- Combined final drafts of each section into a single document.

Following research, the Lit review team found that there is an importance of diversity in clinical trials. A lack of participation from underrepresented populations in clinical trials has led to the development of treatments that are not well-adapted for real world settings or use in the overall population.

Some of the key findings from our research include:

- White people are disproportionately represented in clinical trials, making up 83% of research participants despite being 67% of the population.

- Black and Latino people are often underrepresented in clinical trials
- Clinical trial participants were, on average, younger than the age group most impacted by CLL
- These disparities are caused by a combination of policies, procedures, and barriers to participation.

Environmental Scan

The Environmental Scan team examined comparable nonprofits that had DEI commitments or initiatives to identify comparable organizations for interviews. The Environmental Scan team asked representatives from participating organizations questions related to implementation of DEI initiatives, board development, DEI staff trainings, and broader healthcare system related issues such as connecting with underserved communities. The environmental scan group's methodology included:

- Identified 26 healthcare-based nonprofit organizations
- Selected 7 organizations with robust DEI commitments to request interviews from.
- Interviewed representatives from 4 of the 7 organizations contacted.
- Analyzed interview responses to formulate a list of recommendations.

Following their methods used, the team found that:

- DEI work must be geared towards **changing the hearts and minds** of all people. It is about creating more inclusive cultures within organizations.
- Leaders should recognize and **embrace** that there will always be **challenges** (internal and external) to DEI work.
- Internal initiatives should be focused on **more than just "diversity,"** but also training and conversations surrounding anti-racism, implicit bias, and inclusive language.
    - This may be as simple are trainings within the organization or go as far as providing trainings for physicians

Partnerships

The Partnerships team identified well-positioned, highly recommended organizations to recommend as potential partners for CLL Society. Potential partners were selected based on having services or resources that align with the needs identified in other sections of this report or which had useful networks for disseminating information. The Partnership team has situated these suggestions at the end of relevant sections along with highly detailed descriptions of organizational information pertinent to CLL Society's own DEI initiative.

The Partnerships team looked for organizations that matched the criteria listed below:

- Highly respected organizations with national prominence, successful track records, and innovative approaches
- Well-positioned with appropriate services, resources, or networks to help meet the needs of DEI initiatives
- Committed to social responsibility, with a mission & ethos aligned with CLL Society's goals
- Minority-owned and/or integrate diverse perspectives & sensibilities into their work

Following these criteria, the Partnerships team identified three organizations as potential consultants for social-media and marketing and three organizations as consultants for further Diversity, Equity, and Inclusion work. Based on the recommendations from the Community Outreach team, the Partnerships team identified potential partners along four different paths of outreach, for a total of fourteen organizations.

Brand Review

The Brand Review team explored the current state of branding, both internal and external, for CLL Society which included:

- Analysis of social media channels
- Comparison to similar nonprofit organizations branding strategies
- Creation of recommendations on how to implement a DEI lens in internal and external branding spaces

Along with three recommendations, the Brand Review team created four other deliverables to help enhance the DEI lens of CLL Society's branding strategy.

- A group of specific DEI principles to guide the future branding work of CLL Society
    - The core of the analysis and recommendations relies on the **ARCTIC** Plan: Advocacy, Respect, Compassion, Transparency, Inspiration, and Continued Learning
- A checklist based on the **ARCTIC** Plan that can be used for each post or social media campaign. This will ensure that at least one part of the plan, and ultimately one element of DEI, is included in all content.
- Timeline document for implementing the DEI branding strategy. This outlines steps to take to execute our findings and guide the social media branding for CLL Society in the coming months.
- Mock deliverable content. The team created some examples of a human centered approach to branding. A tweet, Facebook post, and Instagram post were included. This also emphasizes that Instagram can be a new space for CLL Society to reach a younger audience.

Community Outreach

The Community Outreach team worked to develop a plan for effectively connecting with the African American community and other identified underserved populations to raise awareness of CLL and point them to resources that will support them in getting their best care. The following steps were taken to reach conclusions and recommendations for the CLL Society.

- Developed and distributed a survey to current CLL Society members through the weekly alert emails as well as posted to the CLL Society website.
- Conducted research based on the barriers that populations face which limit their knowledge and access to the full healthcare system.

After survey findings and research, the Community Outreach team created recommendations to approach a national outreach campaign across four avenues of access which include:

- Black Churches
- Black Barber Shops
- Latinx Health Centers
- Community Health Workers

Using the following core values is what drives the national outreach campaign:

- **Cultural competence,** including religious competence, and recognizing distrust of medical institutions.
- **Community involvement,** including community leadership & member-volunteers, and systematic solicitation of community feedback.
- **Sustainable commitment, i**ncluding consistent access to information & programs, and plans for long-term funding & program design

The national outreach campaign suggests that CLL Society take the following steps:

- **Partner** with recognized, nationally networked organizations with health-specific missions
- **Train** CLL Society staff that will be interfacing with outreach initiatives in cultural sensitivity
- **Create** referral lists for local providers that are culturally & economically appropriate
- **Create & test** culturally competent educational materials & program options

Clinical Trials

The Clinical Trials team focused on the goal to improve messaging around clinical trials as well as regain the trust of minority communities to increase their participation within clinical trials, the team researched three different categories. For each of these categories, a few questions were created to help guide research:

- Communities of Color and Clinical Trials
    - What does participation generally look like for communities of color?
    - Specific techniques that work better when marketing specifically towards communities of color
- Clinical Trials Outside of the CLL Society
    - Generally, how are clinical trials marketed beyond the CLL Society?
    - What are some successes or weaknesses of their messaging, marketing, or other techniques?
- General Mistrust in Clinical Trials
    - Where does mistrust span from? What is the historical context?
    - What is the history of clinical trials? Could the root of clinical trials be tied to mistrust?

With this research, the Clinical Trials team was able to create five recommendations for the CLL Society that align with these areas of research. These are the recommendations:

- Build Better Relationships with BIPOC Clients
    - The CLL Society should focus on targeted and intentional relationship building with BIPOC clientele to ensure their fears and misunderstanding are heard and tackled at the individual level.
- Education Campaigns
    - At a broader level, the CLL Society can run education campaigns. These are a great option because they are extremely flexible. Education campaigns can focus on a variety of topics and be marketed on a range of platforms.
- Utilize Community Spaces and Leaders
    - Many studies have found that the most successful engagement of BIPOC populations is by working within trusted community spaces and alongside community leaders. Churches, barbershops, and more niche networks can be used to combat mistrust and enhance understanding.
- Update Website to Include Most Relevant Information
    - Many pages on the CLL Society website could be updated to include more targeted messaging and storytelling. The CLL Society has a great foundation to add more resources to their website.

- Make Website More Accessible
    - The CLL Society website needs a few updates to help accessibility. Although almost all the website is available in four languages, we recommend that more languages are offered to be inclusive of the increasingly diverse population in the United States. Other aspects of this recommendation include updating the website to help people with disabilities or those with low health literacy.

Board Development

The Board Development team explored best practices in board professional development surrounding diversity, equity, and inclusion. Through research, key takeaways were found within the field of DEI work for organizations as well as possible toolkits, resources, and training opportunities for CLL Society to engage with and implement its internal and external DEI commitments among its board of directors more fully. The following are the key findings and recommendations that the board development made.

- DEI Approach to Board Member Recruitment
    - Findings
        - Diverse boards can generate a wider array of ideas, have higher decision-making autonomy, access more resources, and are more resilient for the future
        - Diversity is becoming of increased importance to funders
        - Non-diverse boards risk becoming stagnant
    - Recommendations
        - Assess current board skills and demographics to identify gaps
        - Define diversity for CLL Society's Board
        - Know the value-add of a prospective board member
- Developing a DEI Board Committee
    - Findings
        - Increases organizational commitment to DEI
        - Helps keep the organization on track for reaching DEI goals
    - Recommendations
        - Create the DEI Committee as an Ad hoc committee as defined by board bylaws
        - Follow the four phases for board committee formation
            - Phase 1: Preparation
            - Phase 2: Establishment of Framework
            - Phase 3: DEI Initiative Implementation
            - Phase 4: Evaluation
- DEI Training and Professional Development

- Findings
    - Creates culture of continuous learning and engagement for the board and organization as a whole
    - Increases organizational performance and capacity-building
    - Need both functional and social inclusion
- Recommendations
    - Both board and staff members should participate in all DEI-oriented training and professional development activities
    - DEI training and professional development opportunities should be both internally and externally facilitated
    - For internal activities, compiling a list of DEI resources (articles, blog posts, self-assessments, films, etc.) can be beneficial
    - CLL Society should commit to both an externally facilitated training in 2022 and hiring a DEI consultant in 2-3 years

Literature Review

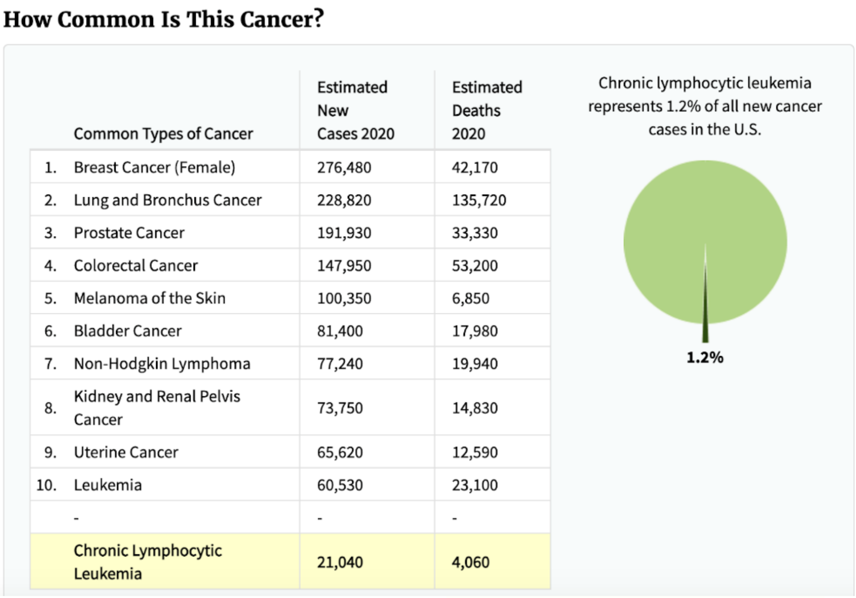
Disparities in Cancer

A major problem that the United States faces in terms of dealing with cancer is due to the existing disparities in cancer. There is an on-going struggle to eliminate or reduce them. The disparities in cancer are differences in cancer measures, including, incidence (the occurrence of new cases), prevalence (already existing cases), stage at diagnosis, survival (how long are people able to survive after occurrence), mortality, morbidity (the complications resulting from cancer), survivorship (includes the quality of life after treatment) and screening rates.[1]

The differences in these cancer measures/disparities can be experienced by certain population groups that can be divided by their age, income, gender, race/ethnicity, disability, education, national origin, and sexual orientation etc.[2] The reasons for experiencing these disparities by populations can stem from biology, genetics, lack of access to health care, low education, distance from screening sites, environmental conditions, health insurance, individual habits etc.[3]

The Prevalence of Cancer by Type

The most common type of cancer is female breast cancer, which had about 276,480 estimated cases in 2020, and 42,170 deaths. Then its lung and bronchus cancer with 228,820 estimated cases and 135,720 deaths. Chronic Lymphocytic Leukemia (CLL) is comparatively much less prevalent. It only represented about 1.2% of all the new cases in 2020, with 21,040 estimated number of cases, and 4,060 deaths.[4]



How Common Is This Cancer?

	Common Types of Cancer	Estimated New Cases 2020	Estimated Deaths 2020
1.	Breast Cancer (Female)	276,480	42,170
2.	Lung and Bronchus Cancer	228,820	135,720
3.	Prostate Cancer	191,930	33,330
4.	Colorectal Cancer	147,950	53,200
5.	Melanoma of the Skin	100,350	6,850
6.	Bladder Cancer	81,400	17,980
7.	Non-Hodgkin Lymphoma	77,240	19,940
8.	Kidney and Renal Pelvis Cancer	73,750	14,830
9.	Uterine Cancer	65,620	12,590
10.	Leukemia	60,530	23,100
	-	-	-
	Chronic Lymphocytic Leukemia	**21,040**	**4,060**

Chronic lymphocytic leukemia represents 1.2% of all new cancer cases in the U.S.

Credit: National Cancer Institute

Cancer Disparities within Groups

Different kinds of cancer disparities exist within the different population groups. According to race/ethnicity, the highest rate of new cancer cases is in the White population i.e., 452.1 per 100,000, and the lowest in Asians/Pacific Islanders at 302.1 per 100,000.[5] At the same time, the death rate is different. The highest death rate is for the Black population at 177.5 per 100,000, for the White population at 156.3 and the lowest for Asians/Pacific Islanders at 97.2 per 100,000.[6]

Similarly, according to almost all races/ethnicities, men are more likely to be diagnosed with cancer than women i.e., 480 per 100,000 men per year and 418 per 100,000 women per year, respectively. Black men have the highest diagnosis for cancer at 515 per 100,000, and then White men at 486 per 100,000. Meanwhile, White women have a higher rate of diagnosis at 432 per 100,000 than Black women at 391 per 100,000. When it comes to death rates though, the situation is worse for Black women. The death rate for that group is 151 per 100,000 as compared to White women, which is 134 per 100,00 even though the cancer diagnosis rate was lower for Black women. Meanwhile, the death for Black males is the highest among all groups according to race/ethnicity and sex, which is 221 per 100,000. In all ethnic groups though, the death rate for men is much higher than that of women. This shows that different kinds of disparities exist when it comes to sex within the different races.[7]

Disparities by Cancer Types

For all types of cancer, black men have the highest rate of new cancer diagnosis. The most common ones include, prostrate, lung and bronchus, and colorectal.[8] In the case of women, White women have the highest rate of new cancer diagnosis, with breast, lung, and bronchus, and colorectal being the most common types of cancer.[9] For all types of cancer, Black men have the highest death rate and so do Black women, therefore, the Black ethnic group overall has the highest death rate for any type of cancer.[10]

Within the different cancer types of certain other disparities, include, the higher death rate of Black women for breast cancer than White women even though they have similar rates of incidence of the disease.[11] In the case of prostate cancer, Black men are twice as likely to die of the disease than White men. For people with colorectal cancer, the likelihood of dying prematurely decreases with the higher level of education. Furthermore, the highest rates of cervical cancer are found in African American and Hispanic women, with African American women having the highest death rates. For kidney cancer, Alaskan Natives have the highest death rates among any other ethnic group. This is also the case for liver and intrahepatic bile duct cancer.[12]

Examples of Geographic and Socioeconomic Disparities

Specific geographic disparities include, for example, that men in the Appalachian region have a much higher incidence for lung cancer (26 percent higher) than men in the rest of the United States.[13] Also, people in Massachusetts are more likely to be up to date for colorectal cancer screening than people in Wyoming (76 percent in comparison to 58 percent).[14]

Socioeconomic disparities include, for example, in the case of cervical cancer, women in the highest income bracket are much likelier to be up to date with cancer screening than women in the lowest income bracket (79 percent in comparison to 59 percent). In metastatic bladder cancer, people with a low socioeconomic status are 50 percent less likely to receive chemotherapy.[15]

Changes in Cancer Disparities Due to COVID-19

One of the ways that COVID-19 has impacted cancer disparities is through the reduction in cancer screening, which is essentially responsible for the detection of ‘precancerous or early cancerous lesions,’ and it has disproportionately impacted minority communities through a sharp decline in screening rates.[16] There is fear that the gains that have taken place with regards to early cancer detection in communities of color may be reversed. Many studies have shown that early detection of cancer has multiple benefits, including the reduction in mortality rates. The 5-year chances of survival increase especially if the cancer is localized.[17]

‘Individuals who are not up to date with cancer screening recommendations are disproportionately found in medically underserved segments of the U.S. population, including racial and ethnic minorities.’[18] For example, White people are 69% up to date with screening in comparison to 66% Blacks, 59% Hispanics and 56% Alaskan Natives for colorectal cancer.[19] Similarly, women in lower income brackets are less likely to be up to date with breast cancer screening than women in higher income brackets.[20]

Due to COVID-19 many cancer screening sites were shut down in March 2020 to prevent the spread of infection. This resulted in a reduction in screening by 89.2% for breast cancer and 84.5% for colorectal cancer in comparison to 2019.[21] The fear of getting infected at a medical site was also responsible for the reduction in screening rates. Furthermore, a reduction in childcare, changes in local transportation, work related issues, potential loss of employment, lack of savings impacted the medically underserved community even more.[22]

Initially, some delays in screening seemed beneficial, but with the increasing period of the pandemic and screening delays, the cancer risks increased. It can be inferred from studies that a 5-year delay in cancer diagnosis can increase death rates by about 8% for breast cancer and 16% for colorectal cancer due to delayed cancer detection.[23]

Cancer screening helps reduce the risk of death from cancer, and it massively helps reduce cancer disparities, but due to the pandemic, there is a great risk that the already existing disparities will considerably worsen.[24]

Case Study: Cancer Disparities in Rural Appalachia

Cancer is unequally distributed in the United States. Even though the cancer mortality rates have declined over the past two decades, there have been geographic disparities in this decline. There has been a lesser decline in the Appalachian region, which includes 12 states from the Eastern and Southern United States.[25] In the case of breast cancer, for example, there was only a 17.5% decline in mortality rates in Appalachian counties as compared to 30.5% in non-Appalachian counties within those states.[26] The cancer incidence is also higher in these regions.

About 25 million people (8% of the US population) live in the Appalachian region. This area has lower income and higher poverty rates than the rest of the US. Even though there are 'highly urbanized areas' such as Pittsburgh, still most of the counties in the area are rural.[27] 8.5 million people lived in rural Appalachia in 2010. These counties suffered economically and were medically underserved. The population in this region was mostly White at 82.3%, followed by 9.2% Blacks.

Yao et al. conducted a study using SEER data from 1969 to 2011, which focused on cancer mortality, incidence, stage of diagnosis and survivorship in Georgia and Kentucky comprising four groups in the region: rural Appalachia, rural non-Appalachia, urban Appalachia, and urban non-Appalachia.[28]

Mortality

Generally, cancer mortality was the highest in the early 1990s, but subsequently decreased for all groups. In the 60s and 70s, the mortality rates were 10% lower in rural Appalachians than urban Appalachians. The former had the lowest mortality rates among all groups. This reversed in 1995, with the rural Appalachians having the highest mortality rates. Overall, cancer mortality declined for all groups. From 2007 to 2011, the rural Appalachians had 195 deaths per 100,000 people, 15% higher in comparison to urban non-Appalachians.[29]

Incidence

From 2000 to 2011, age-adjusted cancer incidence decreased by 6% for urban Appalachians, 7% for rural non-Appalachians, and 9% for urban non-Appalachians. Simultaneously, it increased for rural Appalachians by 6%.[30]

Stage of Diagnosis

In the case of breast cancer, people mostly had early diagnoses in all Appalachian regions. The early diagnosis rate was a little over 80 percent in all groups. For colorectal cancer, the rural non-Appalachians had the highest rate for early diagnosis (54.4%) and the urban Appalachians had the lowest rate (52.4%). However, there were no significant differences.[31]

Survivorship

All cancer patients living in urban non-Appalachian regions had a survival rate of 65% for 3 years and 58% for 5 years.[32] In the case of rural Appalachian cancer patients, 57% survived for at least 3 years and 50% for 5 years. In terms of specific cancer types, for lung cancer, the 5-year survival rate was 12% for rural Appalachians and 14% for urban non-Appalachians, and for prostate cancer it was 78% and 84% for these groups.[33]

Conclusion

The existing disparities in cancer make it tougher for certain populations to deal with the disease than others. The Black ethnic group overall suffers the most due to these disparities, and specifically Black males. It is, therefore, not only important to learn about these disparities but to deal with them to give all cancer patients a relatively equal and better chance of survival.

Disparities within CLL

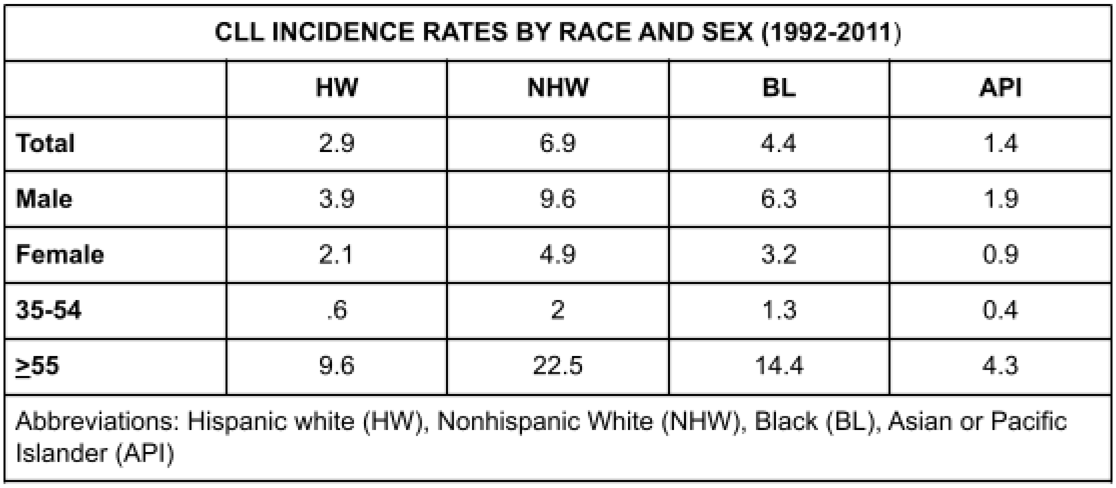
Introduction

The physical characteristics at presentation and outcomes of chronic lymphoblastic leukemia (CLL) patients vary across race, ethnicity, age, and sex. Socioeconomic status also plays a role in survival rates.[34] Notably, data about white and black patients is the most readily available. Studies include Asian/Pacific Islander (API) and Hispanic/Latino patients less frequently and the data on these populations found in the papers reviewed is limited[35,36].

Incidence Rates

CLL is most common in the non-Hispanic white population and less prevalent among Black, Latino, and API populations.[37,38] People of Asian or Pacific Islander descent have especially low rates of CLL.[39] Within each population, those assigned male at birth are more likely to be diagnosed with CLL than women. Overall, older white men have the highest incidence rates of CLL.

Older people are more likely to be diagnosed with CLL than younger ones. The median age of CLL patients at diagnosis in the United States is 70 years old; the most common age of diagnosis is between 65 and 74 years. As demonstrated in the figure below, most CLL patients are between 55 and 84 years old; this is because the disease is more common in older people and because mortality increases with age.[40]

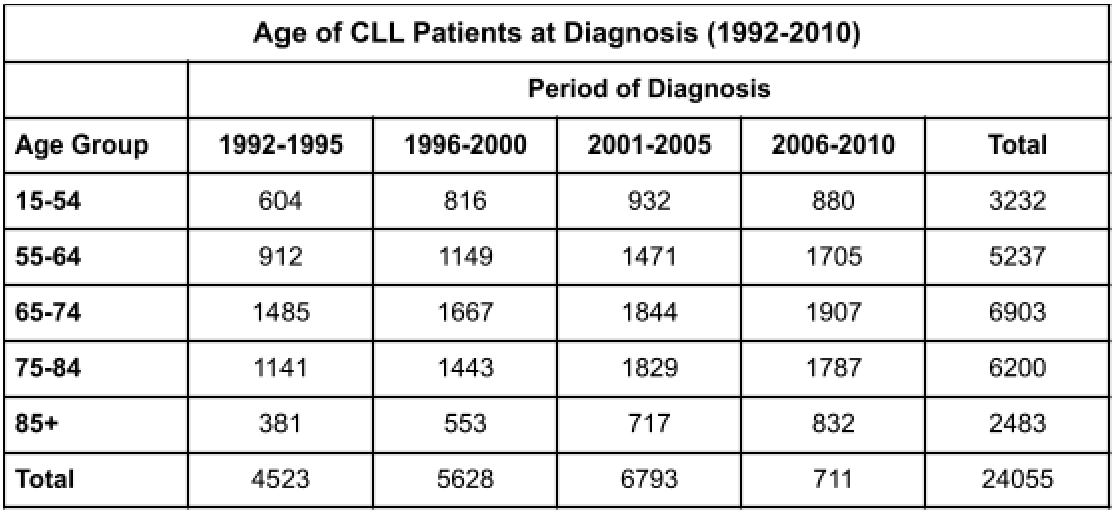


CLL INCIDENCE RATES BY RACE AND SEX (1992-2011)

	HW	NHW	BL	API
Total	2.9	6.9	4.4	1.4
Male	3.9	9.6	6.3	1.9
Female	2.1	4.9	3.2	0.9
35-54	.6	2	1.3	0.4
≥55	9.6	22.5	14.4	4.3

Abbreviations: Hispanic white (HW), Nonhispanic White (NHW), Black (BL), Asian or Pacific Islander (API)

Source: Zhao Y, Wang, Y, Ma, S.



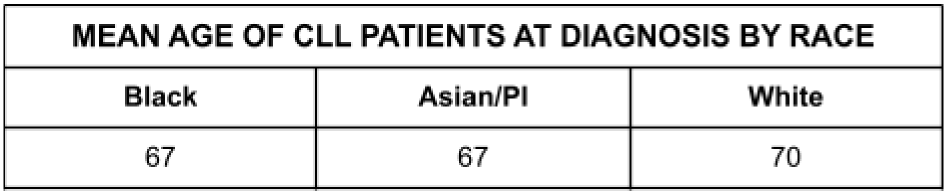
Age of CLL Patients at Diagnosis (1992-2010)

	Period of Diagnosis				
Age Group	**1992-1995**	**1996-2000**	**2001-2005**	**2006-2010**	**Total**
15-54	604	816	932	880	3232
55-64	912	1149	1471	1705	5237
65-74	1485	1667	1844	1907	6903
75-84	1141	1443	1829	1787	6200
85+	381	553	717	832	2483
Total	4523	5628	6793	711	24055

Source: Pulte D, Redaniel MT, Bird J, Jeffreys M.

Characteristics

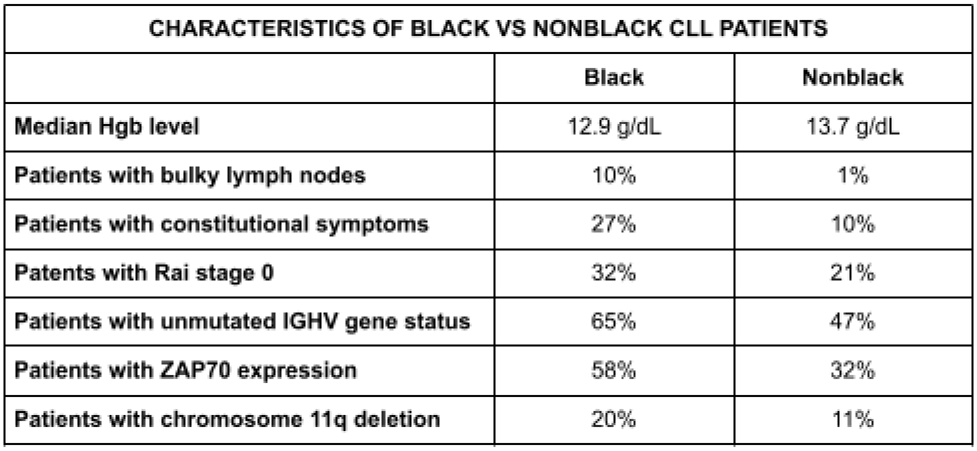
Compared to their white counterparts, Black and API CLL patients are diagnosed at a younger age.[41,42]



MEAN AGE OF CLL PATIENTS AT DIAGNOSIS BY RACE		
Black	**Asian/PI**	**White**
67	67	70

Source: Shenoy PJ, Malik N, Sinha R et al.

Furthermore, Black patients present with more advanced disease progression at diagnosis and have a higher incidence of gene expression and chromosome mutations that are associated with negative outcomes than their nonblack counterparts.[43,44,45] These differences in biological markers, gene expression, and chromosomes are summarized in the table below. The indicators listed below are associated with lower survival rates and worse response to chemotherapy.[46,47]



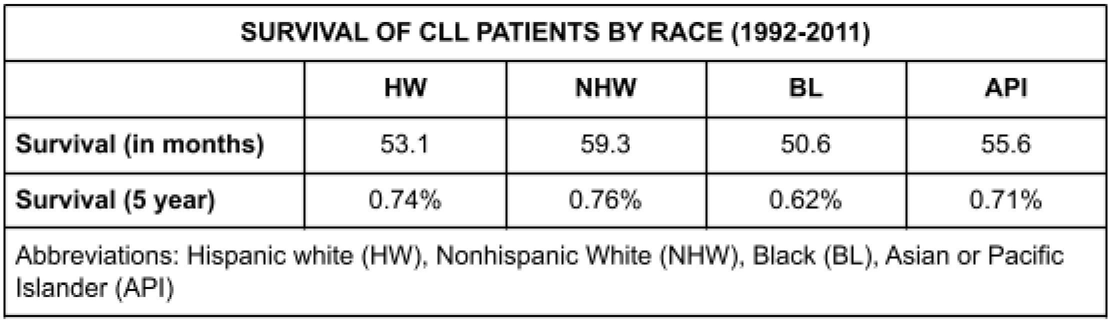
CHARACTERISTICS OF BLACK VS NONBLACK CLL PATIENTS		
	Black	**Nonblack**
Median Hgb level	12.9 g/dL	13.7 g/dL
Patients with bulky lymph nodes	10%	1%
Patients with constitutional symptoms	27%	10%
Patents with Rai stage 0	32%	21%
Patients with unmutated IGHV gene status	65%	47%
Patients with ZAP70 expression	58%	32%
Patients with chromosome 11q deletion	20%	11%

Source: Falchi L, Keating MJ, Wang X et al.

Outcomes

Survival outcomes for CLL patients vary by age, sex, race, and socioeconomic status.[48,49,50,51,52,53] As CLL patients age, their relative life expectancy decreases, especially after age 75 and again after age 85. Even with increases in life expectancy due to improvement in treatments, younger CLL patients see larger increases in life expectancy than their older counterparts.[54] This suggests that the reductions in life expectancy with advanced age are independent of the quality of treatments available.

Similarly, disparities in survival rates between racial and ethnic groups exist independent of the quality of treatments available. Nabhan, Aschebrook-Kilfoy, and Chiu et al[55] demonstrate that racial disparities in survival rates persisted in the second era after the approval of rituximab despite significant improvements in survival rates for Black, Latino, and white non-Hispanic CLL patients. Although API patients saw smaller improvements in survival, the authors suggest that this is due to already having the highest survival rates; the improvement of treatments over time has lessened racial disparities but not eliminated them.[56] The authors also found that socioeconomic disparities in survival rate existed independent of era. Consistent with these findings, Shenoy, Malik, and Sinha et al's[57] examination of CLL survival rates over four time periods also revealed racial disparities. API and non-Hispanic white patients have the best survival rates, followed by Latino patients; Black CLL patients have the lowest survival rates.[58,59,60]



SURVIVAL OF CLL PATIENTS BY RACE (1992-2011)

	HW	NHW	BL	API
Survival (in months)	53.1	59.3	50.6	55.6
Survival (5 year)	0.74%	0.76%	0.62%	0.71%

Abbreviations: Hispanic white (HW), Nonhispanic White (NHW), Black (BL), Asian or Pacific Islander (API)

Source: Shenoy PJ, Malik N, Sinha R et al.

Male CLL patients also have lower survival rates compared to their female counterparts.[61,62] Although one paper showed male and female patients had similar two-year survival rates, female CLL patients had better five-year survival rates.[63] This suggests that in the long term, CLL progresses more quickly and aggressively in male patients.

Causes of Disparities

The cause of disparities in survival rates for CLL patients between racial and sex categories has not been thoroughly examined within the literature examined. However, a few factors have been identified as possible reasons to explore in future research. Socioeconomic status accounts for some of the disparities in survival because of its effect on access to medical care. Members of different racial and sex categories have different propensities to seek medical care as well, which also affects diagnosis and treatment of illnesses.[64] Another cause for racial disparities in CLL survival rates is the possibility that Black and Latino patients may be less likely to receive transplants. Finally, differences in genetic aberrations discussed earlier also play a role in disease severity, response to treatments, and life expectancy.[65]

Research Quality

The research papers included in this section use a variety of methodologies to examine trends in differences in CLL incidence rates and outcomes between different populations yet draw similar conclusions. Nabhan, Aschebrook-Kilfoy, and Chiu et al[66]; Pulte, Redaniel, and Jeffreys et al[67]; Shenoy, Malik, and Sinha et al[68]; and Zhao, Wang, and Ma[69] analyzed data from the Surveillance, Epidemiology, and End Results (SEER) Program database, which may have contributed to the similarity in results. However, each group of authors examines different time periods, which suggests that the trends they identified are stable over time.

SEER data includes about fourteen percent of the U.S. population and is representative of the U.S. population in terms of race and ethnicity.[70] Differences between the SEER population and the general U.S. population include higher affluence and a higher proportion of foreign-born persons.[71,72] One limitation of the SEER database is that it is broader and more generalized due to data being collected at the population level rather than the individual level.[73]

Nabhan, Aschebrook-Kilfoy, and Chiu et al compared SEER data from two eras preceding and following the FDA approval of rituximab to examine the effect of new treatments on disparities in CLL outcomes. [74] Zhao, Wang, and Ma use data from two overlapping time periods in their analysis. [75] These authors draw upon SEER data from 1992-2011 to analyze the incidence of Leukemia subtypes and the characteristics of patients; meanwhile, survival analysis is from SEER data collected between 1992 and 2006. Similarly, Shenoy, Malik, and Sinha et al compared SEER data from four time periods to account for changes in treatment in their analysis.[76]

By contrast, Falchi, Keating, and Wang et al analyzed medical records of newly diagnosed CLL patients between 1997 and 2011 from two hospitals in Texas.[77] The authors compared several characteristics and outcomes such as age at presentation, time to treatment, and survival rates of black and nonblack patients. Although the sample size is relatively small compared to papers which reviewed SEER data, this paper was able to compare response to treatment. More broadly, Zavala, Bracci, and Carethers et al examined a broad variety of literature to analyze disparities in cancer in the United States.[78]

One limitation of this research is the thinness of literature addressing CLL specifically. Many articles focus on Leukemia in general with limited information about CLL. Another limitation of the current literature on CLL is the exclusion of minority populations. For example, there is less data about Latino patients that have CLL. Another gap in the research concerns gender and sexual minorities; there is no mention of transgender or gender nonconforming individuals in any of the literature reviewed for this section. This is an area of medicine that is often overlooked by current medical literature and needs more attention from the academic community.

Disparities in Clinical Trials

Introduction

Over the last decade, governments, funders, and various other stakeholders have placed a stronger focus on the need for greater diversity and inclusion through research systems and clinical trials.[79] An increasing body of evidence supports the case for diversity and inclusion, as do ongoing issues of discrimination, bias, and inequality. Clinical trial participation is disproportionate among adults of low socioeconomic status, racial and ethnic minorities, and those who live in rural areas.[80] Diverse involvement is necessary to determine which interventions are most successful in various groups. As with disparities within open access, civic engagement, and scientific education, CLL Society's scope and impact across the health and global research communities can help to adjust the parameters of such disparities, inspiring broader reform in policies, practices, and cultures.

An inclusive and representative clinical trial should be one that includes a sample that accurately depicts the makeup of the population paying special attention to demographics such as sex, race, and age. Clinical trials should be patient-centric where they work to elevate unheard patient voices and experiences through the development of new treatments and medicine to treat cancer. The absence of clinical trial diversity is not only a medical problem, but a moral and scientific problem as well.[81] Findings can be distorted when trial subjects are homogeneous, resulting in an abundance of medical and clinical knowledge that cannot be generalized.[82] Incorporating a diverse range of people into clinical research could result in more representative and thorough results, allowing for a better understanding of differences in treatment responses and, as a result, a decrease in disparities and inequalities in outcomes.[83] The primary purpose of this study is to undertake a systematic and critical review of participation in clinical trials and identify downstream impacts to populations that are under-represented in these trials. The review draws on evidence from across the research system, with a primary focus on disparities and entry barriers within clinical trials. It also draws on related literatures on diversity, inclusion, and equality across CLL Society systems and services.

Importance of Representation in Clinical Trials

Clinical trial participation by underrepresented groups is a vital connection between medical research innovation and healthcare improvements. Clinical trials must be inclusive and representative of the entire population because they are critical for the development of new methods to prevent, detect, and treat cancer. Clinical trial participation should represent the diversity of the population, with a focus on those who are most affected by the disease. Through clinical trials, researchers can work to determine what treatment methods are safe, effective, and successful in treating cancer. Due to a lack of participation from underrepresented groups in clinical trials, treatments that have not adapted well to real-world application and have not proven effective in different populations have been developed.[84]

Failure to collect medical testing results that adequately represents the diversity of the entire population has a range of consequences, including barriers to external legitimacy and generalizability, denial of any health benefits of study attendance to disadvantaged groups, inability to test the safety of clinical technologies with sub-groups in the population, and failure to recognize groups in need.[85] Many factors contribute to the exclusion of socially disadvantaged people from health and medical studies. These causes must be understood to implement policies to improve vulnerable groups' interest and participation in health and medical research.[86]

Key Findings: Clinical Trial Disparities

Race

The burden of cancer has the greatest impact on racial and ethnic minorities in the United States, so it is critical that this demographic be adequately represented in medical research and clinical trials.[87] However, there is a major gap in participation of minorities in clinical trials, according to a recent study from the US Food and Drug Administration (FDA) on its 2018 Drug Trial Snapshots. White people account for about 67% of the United States population but make up around 83% of research participants.[88] While Black/African Americans make up 13.4% of the US population, they make up just 5% of clinical trial study participants. While Hispanic/Latinos make up 18.1% of the US population, they make up less than 1% of trial participants.[89] A report conducted in the journal Leukemia & Lymphoma supports the existence of this disparity, reporting that white elderly patients had a CLL occurrence ratio of 2.31 times that of Hispanics and 1.48 times that of Blacks/African Americans.[90]

The small number of studies available nationwide and regionally; medical infrastructures without the resources to fund trials; financial impacts to hospitals and patients; stringent research design and registration criteria; and a lack of community engagement are all barriers at the level of health care services and hospitals. Since participants of minority groups are more likely to receive treatment in under-resourced healthcare systems with little clinical trials available, to be underinsured, and to arrive with circumstances that render them ineligible for trials that might be available, all these obstacles have a disproportionate impact on minority enrollment and participation.91 Implicit prejudice towards members of minority communities is another aspect that may deter health care professionals from discussing trials with certain patients. Prior research has revealed that doctors' racial bias (conscious and unconscious) toward members of minority communities affects clinical advancements with minority patients.92 While patients from racial and ethnic minorities are just as likely as white patients to agree to participate in a clinical trial, the reasons for refusing may vary by race and ethnicity. Minority patients may have negative race-related outlooks and beliefs that may affect relationships with their health care provider about trials and enrollment decisions, both directly and indirectly.93 These views, which stem in part from issues of discrimination, poorly informed consent, and inadequate health services for minorities in the United States, include a deeper distrust of medical institutions and health care providers, as well as a stronger feeling of having been discriminated against.94 The most common deterrent to minority patients' willingness to participate in a clinical trial was skepticism of science and the medical system, according to a comprehensive analysis of the research assessing the various barriers to minority participation in clinical trials.95

Clinical trial under-enrollment of racial and ethnic minority groups is a health care inequality caused by preventable and interconnected policies, procedures, and barriers at the system and individual level. Multilevel approaches are likely to be the most successful tool for expanding participation in a well-informed, diverse demographic of patients, even though multiple interventions intended to improve clinical trial enrollment of racial and ethnic minorities and other under-represented groups have had differing degrees of effectiveness over time.[96] Medical researchers will be able to get closer to their target of turning new insights into meaningful outcomes and delivering high-quality cancer treatment for all patients if members of these communities choose to engage in a clinical trial focused on a positive and effective system-level atmosphere and high-quality contact with their health care providers.[97]

Age

Cancer is a condition that corresponds with age, with the number of cancer cases in the United States expected to rise exponentially as the population ages.98 Research is needed to help support care choices for older cancer patients. Despite representing a growing segment of the cancer patient population, adults aged 65 and up, particularly those over 75, are underrepresented in cancer clinical trials.99 While blatant clinical trial guidelines can act as barriers for older patients, age limits are not the only factor that can limit enrollment for this demographic. A 2020 study conducted by the JAMA Oncology reports that two-thirds of the clinical trials listed on clinicaltrials.gov included non-age-related exclusion criteria, such as pre-existing health conditions, that disproportionately exclude older patients.100 Majority of the trials also omitted endpoints focusing directly on the impact of a drug on older people, such as whether older adults were less likely to stick to the medication plan or were more likely to have mobility issues.101 Another study released by JAMA Oncology in 2019 compared the average age of participants in over 300 cancer trials to the average age of patients worldwide with such diseases.102 Participants in the sample were, on average, much younger than the real-world population affected by an illness. Industry-funded research and experiments evaluating a tailored treatment revealed the greatest age gaps. Another concerning result was that the age disparities seemed to be expanding over time.[103]

Due to age-related physiologic shifts, there may be differences in drug response and toxicity between younger and older patients. While barriers such as limited mobility and fatigue can impact older patients' willingness to participate in clinical trials, their ability to do so much not be hindered due to inequalities. Furthermore, older people frequently have comorbidities and may be taking concomitant drugs, both of which may influence the effectiveness of the cancer medicine they are taking, as well as the frequency and severity of adverse effects.[104] Clinical trials must involve a diverse range of older adults who are representative of the intended population, including those who are experiencing physiological decline.

Gender/Sex Representation

In the United States, women and members of the LGBTQ community make up a growing and medically underserved population. Sex and gender are critical health determinants. Rather than biological sex (e.g., male, female), gender (e.g., woman, man, non-binary, etc.) contributes to the cultural, environmental, cultural, and behavioral characteristics and decisions that affect a person's self-identity and health.[105] Although efforts to be more inclusive of women and LGBTQ members have been made over the last decade, this demographic is still under-represented in preclinical, early, and late phase cancer studies.[106]

People of all regions, ages, ethnicities, races, and socioeconomic backgrounds are represented within the LGBTQ community. Compared to that of their heterosexual counterparts, LGBTQ individuals have a much harder time accessing and utilizing healthcare services due to marginalization. A recent study released by the National Institutes of Health reports that in comparison to the 10% of heterosexual adults, nearly 30% of LGBTQ adults do not have a consistent healthcare provider, and do not seek healthcare resources or services.[107] LGBTQ individuals in the United States face obstacles to obtaining health insurance coverage and may forego treatment due to financial constraints. Patients who identify as LGBTQ are more likely to keep quiet about serious health problems for fear of being stigmatized.[108] Despite the urgent need for health services in the LGBTQ community, social obstacles to clinical information and treatment play a major role in the avoidance or postponement of seeking care or enrolling in clinical trials. An abundance of medical professionals is unaware of the healthcare needs of LGBTQ patients, and some have hostile attitudes toward them. According to studies, there is a lack of confidence and understanding in physician-patient relationships because patients are afraid of receiving subpar treatment or having their confidentiality violated if they reveal their sexual orientation or gender identity.

Despite significant progress in attempts to involve more women in clinical trials, disparities in healthcare quality and services continue to exist. To gain medical knowledge and equity, female participation in health research and trials must be proportionate.[109] The reproducibility and generalizability of outcomes are reduced when trial participants do not represent disease incidence. Data from clinical trials conducted on men does not always apply to women. A 2018 study released by the American Association for Cancer Research reports that a woman's risk of having an adverse reaction to a drug is 1.5 to 1.7-fold higher than a man.[110] Another 2018 study revealed that just 38% of the 5157 patients that took part in oncology clinical trials that led to the FDA approval of over 16 new drugs were women.[111] Many of the obstacles to women enrolling in clinical trials are common to all patients, including a lack of knowledge of trial opportunities, restricted trial availability, and excessively strict eligibility requirements. Study burden and inconvenience, mistrust of researchers and research institutions, lack of understanding of the significance or function of clinical research, and fear of danger and randomization are all patient-specific factors that affect women.[112] Medical professionals' negative attitudes about women as research participants can also play a role; these include misconceptions that women are more challenging to recruit, that women are more prone to reluctant participation, and that women burden scientific design with complexity.[113] Improving the recruitment and retention of women and LGBTQ patients in clinical trials necessitates a multifaceted approach that includes physician education on gender inequalities as well as expanded collaboration with community stakeholders and organizations to assist with clinical trial redesign and community education.[114]

Conclusion

In conclusion, there are many obstacles to equity and inclusion in cancer trials for underrepresented groups. According to the literature, a renewed focus on inclusion and diversity in clinical trials is both relevant and timely. Considering the volume and complexity of identified barriers to participation, well-designed trials using appropriate measures and procedures are urgently needed to identify key determinants of knowledge, ability, and support of participation. Cancer prevention, screening, and high-quality cancer treatment are all at risk for these under-represented populations. To correct this, obstacles to effective treatment and outcomes must be addressed at several levels, including interpersonal and structural barriers. A concerted effort is needed to improve patient and caregiver education, improve outreach and assistance, provide training and education, provide health care staff who are aware of and responsive to community needs, and promote constructive policy and institutional action.

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Environmental Scan

Overview

This section of the report details the background, methodology, and overall findings of our environmental scan. We focused our scan on healthcare-based nonprofits with diversity, equity, and inclusion (DEI) commitments or initiatives. After identifying organizations, conducting interviews, and analyzing our notes, we developed a list of key takeaways for CLL Society to consider throughout the organization's DEI journey.

Background

The need for meaningful DEI initiatives within the healthcare field is an increasingly pressing matter. In recent years, healthcare-related organizations such as the Financial Healthcare Management Association, the American Hospital Association, and the American Association of Medical Society Executives have begun engaging more directly with and writing articles focused on the need for DEI initiatives in the healthcare field. In addition to the statements from these organizations, searches using terms such as "DEI initiatives" or "equity initiatives in healthcare" turn up hundreds of articles from within the last year. Throughout the healthcare field, many organizations are taking DEI, both internally and externally, more seriously. While all organizations are at different stages in the process and are approaching DEI in numerous ways, DEI initiatives are increasingly relevant and necessary to creating more equitable workplaces.

With this in mind, we conducted a scan of organizations within the healthcare field that have implemented some form of DEI initiative. We decided to take this approach as sections of what would normally go into an environmental scan, such as an internal look at the board or a review of relevant literature, fit into the scopes of other teams. To best capture what other organizations were doing, we identified several potential organizations, reviewed those organizations online and social media presences', and conducted interviews with key staff involved in the implementation of DEI initiatives.

Methods

To begin our scan, we conducted research and compiled a list of 26 healthcare organizations primarily focused on providing some level of support to cancer patients and their communities. After this preliminary scan, we focused on identifying organizations with DEI commitments or initiatives available on their websites. These commitments or initiatives included efforts such as specific programs focused on providing services to underserved communities, diversity or inclusion statements, or statistics and language reflecting an understanding of DEI work. From this research, we identified seven potentially comparable organizations to contact about interviews.

Note: To protect the privacy of the organizations interviewed, the methods, findings, and references sections have been edited down for this publicly available version of our report.

Conclusion

Through our environmental scan, we found that DEI initiatives are increasingly relevant and needed within healthcare-based nonprofits. After researching, identifying, and interviewing comparable organizations, we developed a list of key takeaways (included in the appendix) as well as general takeaways for CLL Society. We recommend that CLL Society continue to observe and learn from other nonprofits as the organization embarks on its own DEI journey of awareness-building around and implementation of DEI initiatives to build a more inclusive workplace.

Environmental Scan Key Takeaways

Engaging Employees

- DEI work must be geared towards changing the hearts and minds of all people. It's about creating more inclusive cultures within organizations.
- Expanding DEI work to multiple areas of focus can help create broader changes within organizations.
- DEI initiatives should recognize the dangers of and work to avoid tokenism.
- Leaders should recognize and embrace that there will be challenges to DEI work.
- Organizations should focus on the individuals already committed to DEI initiatives.

Internal Initiatives and Training

- Internal initiatives should be focused on more than just "diversity," but also training and conversations surrounding anti-racism, implicit bias, and inclusive language.
- Employee Resource Groups (ERGs) can help provide affinity spaces for people to collaborate with and support one another within a workplace.
- It is important to provide training and professional development opportunities to everyone within an organization.
- Consultants can help organizations discern unique training needs.
- Requiring or encouraging the universal public display of preferred pronouns on email signatures, Zoom accounts, and other communications builds more inclusive culture.

Board Development

- Successful implementation of DEI initiatives requires support from the board.
- Long term DEI work requires more accurate representation on the board.

Outreach

- Organizations should share information as broadly as possible to expand community accessibility and engagement with DEI initiatives.
- Maintaining a robust online platform is the most effective way to reach an organization's broader client and supporter community.
- The best way to combat misinformation is to spread correct or truthful information.
- It is important to recognize the need for and invest more intentionally in outreach and support to rural communities.
- Organizations can expand their outreach by providing DEI-related trainings and workshops for other organizations.

Social Media

- Despite its importance, it can be challenging to incorporate more inclusive imagery into social media posts while not alienating or tokenizing current clients and donors.
- By posting about DEI work more publicly, organizations signal to stakeholders about their DEI commitments and initiatives.

Policies

- Internal DEI-related policies are most equitable when drafted by legal experts.
- It is important to create outside networks for reporting harassment or abuse.

Challenges to DEI Initiatives

- DEI work takes time, money, and a concentrated effort.
- People are more likely to say they want change than to actually be willing to make those changes and be committed in the long run.
- By fully committing to DEI work, organizations may lose some stakeholders along the way. While challenging, this is natural with all kinds of organizational change.
- Much of the healthcare industry is not adequately embracing DEI work as a way to address disparities in the field.
- The broader medical system is not always set up for accessibility, complicating organizational initiatives for equitable services, supports, and resources.

Brand Review

Overview

The Brand Review team explored the current state of branding, both internal and external, for CLL Society and the desired state of branding. This included an analysis of social media channels, comparison to similar nonprofit organizations branding strategies, and ultimately the creation of recommendations on how to implement a DEI lens in internal and external branding spaces. Along with our three recommendations, we created some tangible tools like checklists, timelines, and a group of principles to guide the future branding work of CLL Society. The core of our analysis and recommendations relies on the **ARCTIC** Plan: Advocacy, Respect, Compassion, Transparency, Inspiration, and Continued Learning.

Background

Before diving into the brand analysis of the organization we wanted to gather a holistic view of CLL Society and what it offered its community members. As we analyzed CLL Society's mission and value statement while looking at their previous engagement with their website and social media, it was clear that they had a solid foundation however the lack of awareness caused friction in taking their organization to the next step. The external social analysis of their competitors along with the internal activation of CLL Society notified us that we needed to incorporate more humane insight in terms of the organization. Creating a more open, clear, and minimalist content can motivate the target audience, in addition to their families understanding the messaging CLL Society is trying to achieve. By altering the perspective of culture and human interaction, we were able to emphasize our newly implemented DEI principles into social content motivating CLL Society to take a stand amongst the social injustices in America while promoting health equity for all.

Methods

After a brand analysis, our team has proposed three recommendations. Before we review these recommendations and steps, we want to establish the process it took to come to these conclusions. The first step in our brand analysis consisted of reviewing CLL Society's social media accounts and analyzing its most popular content. This resulted in the examination of the Tweets and Facebook posts within the past year, noting their interaction levels, time of posting, and content. Twitter and Facebook are the only two social media channels that CLL Society uses as of February 2021. The second step of our analysis was to consider similar nonprofit health organizations and their branding strategies. We examined the branding of the Leukemia and Lymphoma Society's Facebook, Twitter, and website and Patient Power's Facebook, Twitter, Instagram, and website. The third step was to create a set of diversity, equity, and inclusion principles to guide the branding and content of CLL Society. The fourth and last step of our brand review analysis was to compare content against one another, compare content against the DEI principles created in the previous step, and to apply basic marketing principles to the marketing strategy currently in place.

Findings

CLL Society posts regularly on Facebook while having little engagement on each post. It seems that regular short-to-medium length text posts and short text and single image posts do well. Due to the scientific nature of CLL Society's work, the language can sometimes be complicated and difficult to understand for those new to CLL Society's work. There is a lack of DEI-focused posts and content coming from CLL Society channels. No anti-racist or anti-biased content has been shared. To reach the widest audience and commit to true diversity, equity, and inclusion, internal and external branding should always consider the core values and principles of the organization. Intentionally DEI-focused content should be created and planned for. Below is a snapshot provided of elements of our branding scan.

BRANDING SCAN
CLL Related Social Media Snapshot

Organization	Medium	Type	Engagement	Content	Date	Time
CLL Society	Facebook*	Post	40 likes; 14 comments	Mask photo, caregiver, personal photo	11/17/2020	11:58 PM
CLL Society	Facebook	Post	46 likes; 17 comments	10-year anniversary post pinned, requested donations	11/25/2020	11:25 PM
CLL Society	Facebook	Post	126 likes, 31 comments	CLL Society founder posts about losing a friend	1/24/2021	12:35 PM
Patient Power	Facebook	Event	12 guests interested	*Ask the Expert*: Live Q&A with CLL specialists (Zoom)	2/16/2021	2:00 PM
Patient Power	Twitter	Tweet	5,502 followers; following 1,926	Connecting patients and followers to resources, statistics, further education	2/16/2021	5:13 PM
LLS	Facebook	Page	403,055 followers	Multiple posts per week; Facebook direct fundraising capability	**	**

* *CLL Society Facebook page has 2,317 likes*

Conclusions

Ultimately, the branding strategy for CLL Society needs to do several things: make their branding strategy more precise, create more accessible content in terms of language, and make intentional DEI-centered content. Along with our recommendations, we have provided tools and suggestions to accomplish these recommendations (Appendix B).

CLL Society's Commitment to Diversity

To fully promote CLL Society's newly advertised branding, CLL Society must acknowledge that this commitment is an educational journey towards sustainable diversity, equity, and inclusion practices that must be led by CLL Society's organizational mission and deeply rooted in their values. We believe that these policies and practices will strengthen CLL Society's ability to carry out their organizational principles while building community through patient education, advocacy, support, and research. At CLL Society, they envision a world in which everyone can equitably access quality education, support, and care to lead to healthier and happier lives.

CLL Society's commitment to diversity and inclusion is a principle-based approach that values empowering diverse groups of people to join our community and feel welcome here. These core principles are detailed within our **ARCTIC** Plan (see below).

Recommendations

Recommendation #1: Make the general marketing strategy and branding more precise.

Successful engagement through branding does not need to come from posting frequently, but rather the content engagement. CLL Society posts regularly on Facebook while having little engagement on each post. Posting less frequently, one to three times per week, would be recommended. Along with adjusting posting frequency, CLL Society should examine the Facebook insights to page interactions. CLL Society should understand what times their audience is most likely to engage and plan their marketing schedule accordingly. A post at 9am might have a vastly different engagement than a post at 11pm. For content to reach the widest audience, it should be posted and available when much of the audience is already in that space and ready to connect. Along with posting less frequently and being conscious of posting times, CLL Society should analyze what format of posts get the most engagement. It seems that regular short to medium length text posts and short text and single image posts do well.

A summary of steps to make more precise branding are as follows:

1. Post less frequently (1-3 times weekly)
2. Determine the time of highest interactions with audience
3. Determine highest engagement medium

Recommendation #2: Make branding materials more accessible in language.

Due to the scientific nature of CLL Society's work, the language can sometimes be complicated and difficult to understand for those new to CLL Society's work. This can discourage interested clients in participating and further contribute to a smaller audience not interacting with CLL Society. High-interaction content spaces like blog posts and newsletters should have a communication lens if anyone could understand this if they are new to the space. This will require a simple review of high-interaction material before it is released. The language does not need to be changed completely but given more context clues or explanations within the content.

Recommendation #3: Incorporate DEI principles and branding lens for all materials and content.

To reach the widest audience and commit to true diversity, equity, and inclusion, internal and external branding should always consider the core values and principles of the organization. We have created a list of DEI principles that we suggest CLL Society implement. These principles will be the first step in moving the CLL Society brand towards a DEI-centered approach. After these principles have been approved by CLL Society leadership, they should be intentionally and carefully rolled out to the public through the recommended steps below:

- CLL Society should share a press release about how they are seeking equity and diversity in their services and engagement. The press release can focus on this capstone collaboration and the intentional seeking of a DEI plan. It should also mention the guiding DEI principles that will be used in CLL Society content moving forward.
- CLL Society should create a blog post about its commitment to diversity, equity, and inclusion. As the blog is one of the strongest engagement pieces of the website, this will show the serious commitment that CLL Society is making towards these efforts.
- CLL Society brand spaces should do specific posts and events about their new commitment to DEI. For the first 1-3 months, posts can center around DEI initiatives and topics. Consistent messaging can be created by following a DEI checklist for each post. We have provided a DEI checklist for posting in Appendix A. This will help solidify the new branding perspective and create a system where DEI becomes a natural part of the branding process.

Suggested ideas for these posts and events are listed in Appendix C, and include:

1. Town Hall meetings
2. Zoom meetings

3. Share from DEI-centered patient and client care pages
4. Utilize the support groups in a unique way

ARCTIC Plan

As CLL Society moves forward with branding, they can consider a simple checklist to ensure that the DEI principles are being included. The checklist can be like the elements below:

Advocacy

A fundamental part of the CLL Society mission, with the goal to provide advocacies for all and provide inclusive resources and environment to promote education for the CLL community. A fundamental part of enabling this engagement in our team members involves a deep level of trust between team members and our community. CLL Society advocates for and empowers its team members through a variety of initiatives, as we have an incredible opportunity to attract and retain a diverse group of community members to help bring awareness to CLL.

Respect

An ageless principle, and the most important one as it underlies every other principle. Respect communicates that we appreciate, value, and believe we can learn from each of our colleagues. Respect means we value one another's unique characteristics and experiences and assumes that we will be made stronger as we benefit from these diverse characteristics and experiences.

Compassion

Helps the CLL Society become great educational leaders and create resources for our community as we interact with one another. Compassion makes us not only transparent, but eager to learn from each team member and each interaction, including opportunities for improvement. CLL Society is motivated to improve the health and welfare of the community through compassionate conversations and putting our patients' needs first. In promoting compassion at CLL Society, we are encouraging the input and feedback of our community members to help build our educational awareness for future generations to come.

Transparency

It is inclusivity in practice, as it invites every community member to be a part of the solution and holds leadership accountable for solving problems. At CLL Society, transparency is the mechanism through which we exercise compassion and humility, admitting that we do not always get it right, and, most importantly, commit to making it right. Transparency coupled with humility made it possible for us to get back on our intended trajectory of creating an inclusive culture driven by respect.

Inspiration

Allows new and informed current conversations about the role of DEI in the development and evaluation of the patient-centric nonprofit organizations. CLL Society will explore the role of race, ethnicity, and gender in areas such as healthcare, patient organizations and resources to promote inclusivity, awareness, and community development. Among the questions we will ask are: How can we integrate the voices, perspectives, and lived experiences of historically underrepresented individuals into our CLL community discussions? What role can a focus on equity play in helping patients, community leaders, and other healthcare stakeholders reduce structural inequities?

Continued Learning

Allows our team members to challenge themselves through training and development efforts. CLL Society advocates are committed to continued learning to hone professional expertise and maintain knowledge of current conditions in a rapidly changing healthcare environment. CLL Society intends on creating a detailed training program aimed at enhancing the skills and knowledge of our people, including executive coaching, a mentoring program, and a talent management process designed to foster equitable employee development.

Appendix A

✓Branding Checklist

This checklist is designed to be used before each external branding opportunity (i.e. Facebook post, Tweet, external workshop etc.) Ensure that you have hit a minimum of one DEI principle and both final items. This will ensure that DEI principles are connected to all external branding and allow it to become part of the tone of CLL Society. Make sure your content is ARCTIC!

☐ Advocacy

- Advocacy maintains the goal to provide advocacy for all and provide inclusive resources and environment to promote education for the CLL community. Does this content develop a level of trust between team members and community? Does this content work to advocate for CLL Society clients and stakeholders? Does this post target and advocate for a particular group within the CLL Society community?

☐ Respect

- Respect communicates that we appreciate, value, and believe we can learn from every member of the CLL Society community. Does this content value one another's unique characteristics and experiences and assumes that we will be made stronger as we benefit from these diverse characteristics and experiences?

☐ Compassion

- CLL Society is motivated to improve the health and welfare of the community through **compassionate conversations** and putting our patients' needs first. Does this content encourage the input and feedback of our community members to help build our educational awareness for future generations to come? Does it have a social emotional connection?

☐ Transparency

- Transparency is inclusivity in practice, as it invites every community member to be a part of the solution and holds leadership accountable for solving problems. Does this content own up to solutions or process? Does it invite a lens of transparency?

☐ Inspiration

- Inspiration allows new and informed current conversations about the role of DEI in the development and evaluation of the patient-centric nonprofit organizations. Does this content integrate the voices, perspectives, and lived experiences of historically underrepresented individuals into our CLL community discussions? What role can a focus on equity play in helping patients, community leaders, and other healthcare stakeholders reduce structural inequities?

☐ Continued Learning

- Does this post illustrate a desire of continued learning? Is this content an example of growth from previous ideals or lessons? Does this content encourage growth?

☐ Is this content being shared across social media spaces? Has the content been adjusted to each medium?

☐ Has this post been scheduled? 6-8pm is a high engagement posting time*

Appendix B

Social Marketing Implementation Guide: Summer 2021

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

Phase #1

Determine which social media outlets garner the most attention, as well as times of day with highest interaction.

Phase #2

Tailor language and content to the average consumer. It can be difficult for people to understand scientific jargon!

Phase #3

Create a blog post about your new commitment to diversity, equity, and inclusion. The community should see your hard work on display!

Phase #4

Focus on posting content 1-3 times per week. Social media posts should be short and sweet, but attention grabbing.

Future Plans

Continuously monitor how your audience is engaging with content to further promotion of CLL Society's brand.

Appendix C

Suggested Minority-Owned Social Media, Marketing, and Design Companies

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

Partnerships looked into over 30 digital media and marketing companies and picked these three based on reviews and experience working with nonprofits. Each of the three is minority-owned and capable of delivering a wide range of services.

Social Driver
Website: https://www.socialdriver.com/
Contact: hello@socialdriver.com

Their pitch - Social Driver is a leading digital agency with in-house expertise for using social media, digital strategy, content and video, websites, and brand design to have an impact for a brighter future. Our culture is focused on partnership, creativity, stewardship, collaboration, and service.
Our findings - Well reviewed experience working with nonprofits. They have worked with cancer focused nonprofit organizations similar to the CLL Society, including the Leukemia & Lymphoma Society.

Sensis
Website - https://www.sensisagency.com/
Contact - Jonathan Hastings - jhastings@sensisagency.com

Their pitch - Marketing needs meaning to build sustainable demand across cultures. We look for cross-cultural insights to inform our work, bringing purpose and emotional resonance to our clients' marketing efforts. The tools we use require applying equal parts empathy, creativity and technological expertise, building digital brand experiences that ultimately make people's lives better.
Our findings - Sensis are well reviewed and offer a broad range of services and have worked with several nonprofits and government agencies.

The Tactile Group
Website – https://www.thetactilegroup.com/
Contact - info@thetactilegroup.com

Their pitch - The Tactile Group is a full solution digital agency that has been communicating with technology since 2004. We partner with local, state, and federal governments, as well as enterprise and non-profit clients to to help solve complex business problems. We are dedicated to developing products that improve the lives of others. We are committed to working with government, enterprise, and non-profit organizations that feel the same.
Our findings – The Tactile Group is both a digital marketing and IT company that has done extensive work with nonprofit and government agencies.

Community Outreach

Overview

CLL impacts various groups disproportionately for a variety of reasons. Socioeconomic status, racial and ethnic differences, and genetic variants are also factors to consider. Moreover, these patient populations often face actual and perceived obstacles when trying to gain full access to the healthcare system. As a result, there is a pressing need to improve targeted outreach programs for these high-risk populations. When creating such initiatives, keep in mind that there is no such thing as a homogeneous society, but rather a diverse population, as with any broad demographic grouping. Since these various groups will have different criteria and needs, outreach efforts must be broad in scope and tailored to individual, local communities to reach all target audiences. The primary goals of these outreach initiatives must be to increase disease awareness and education among patients that are facing disparities. To accomplish this goal, a diverse variety of groups must be directly involved, including national and—more importantly—local community-based patient associations, hospital management corporations, and local media to publicize the outreach programs.

Background

Community Outreach

Community participation by underrepresented groups is a vital connection between medical research innovation and healthcare system improvements. Community outreach and education strategies must be inclusive and representative of the entire population because they are critical for the development of new outreach methods to prevent, detect, and treat cancer. Community participation and education should represent the diversity of the population, with a focus on those who are most affected by the disease and those who have been underrepresented over time.

An inclusive and representative community outreach initiative should be one that accurately depicts and includes the target population, paying special attention to demographics such as sex, race, and age. Community outreach and education should be patient-centric where they work to elevate unheard patient voices and experiences through the development of communication and engagement strategies. To meet the burden of a significant health disparities agenda, cultural and literacy aspects must be integrated into the implementation of outreach programs, messages, and initiatives. Community outreach is an important vehicle for reducing the discovery-delivery disconnect by bringing CLL education and engagement services directly to community members.

Education in the Community

The value of health education cannot be overstated when it comes to creating a healthier society. To promote health and well-being and ensure equitable access to services, community health workers partner with all members of a community, from residents to government, education, and medical officials. Community health education examines the overall health of a community, attempting to recognize health problems and patterns within a demographic and working with partners to discover alternatives. Community health educators seek to ensure that all members of a community have fair access to wellness opportunities and healthcare programs, in addition to delivering educational resources and programming. Our research reports that common disparities can include, but are not limited to socioeconomic disparities, racial or ethnic disparities, age disparities, gender disparities and rural health disparities.

One method for promoting health quality and disease prevention strategies is by health education. Community education offers opportunities to learn about various health issues. Health education programs are geared to the demographics of the people who would benefit from them. In a suitable environment, health education offers information to target audiences on specific health issues, including the health benefits and risks they pose, as well as opportunities to develop resources and promote behavior improvement. While CLL Society does offer support groups and education, those efforts only get organizations so far so long as disparities within these groups continue to flourish. The overarching purpose of the health promotion and disease prevention initiative can be enhanced by health education programs. To maintain cultural integrity, materials produced for health education services must be culturally appropriate and customized to the target populations. This includes tackling linguistic, locational, and cultural gaps in rural populations, as well as possible obstacles and barriers to health promotion and disease prevention.

Methods

A conditional branch survey was designed with Qualtrics software and made available on the CLLSociety.org website from March 9 to March 24, 2021. A total of 46 DEI-relevant questions centered on current participation, barriers to access, current services and resources, and demographics. The approximately 7,500 members of the weekly CLL Society Weekly Alerts email list received a request to participate, and a social media push for participation was also sent out. The survey was available to all website visitors to open it up beyond only those actively participating in CLL Society services and events. Our analysis is based on data from the 225 responses gathered over the two-week period.

Limitations include a small sample size of self-selecting participants, nonresponse bias particularly the exclusion of those without internet access or who are not aware of the CLL Society or its website, and the two-week time constraint. In context of these limitations, the data revealed useful information and perspectives from the respondents that can inform recommendations for DEI-focused community outreach and engagement.

Findings

Key Findings from Survey Results

- Most people did not participate in support groups because they did not feel they needed support, or they did not have or were aware of support groups in their area.
- Many survey participants currently engage though the different forms that the CLL Society is providing such as: their website, weekly alert emails, webinars, and Dr. Koffman’s blog.
- One common trend within the comments of the support group users is the concern when not everyone in the group is heard. It is important that the group leaders of support groups take the time to make sure everyone is heard within their group. Specific comments include:
    - “Group is often dominated by a few individuals”
    - “Some people are not as talkative and may get left out of the conversation. This month the approach changed to call on every participant, which gave everyone the chance to speak.”
    - “The more members participate, the more I learn.”
    - “New people are given the floor and no one else gets time to update their own situation.”
- Specific comments about people who are not adequately represented in CLL Society support group:
    - “all caucasian”
    - “few people of color, few people who’ve had treatments”
    - “racial and ethnic populations”
    - “we are all white, about 50% by sex, and mainly retirement age.”

Survey Results: Highlights

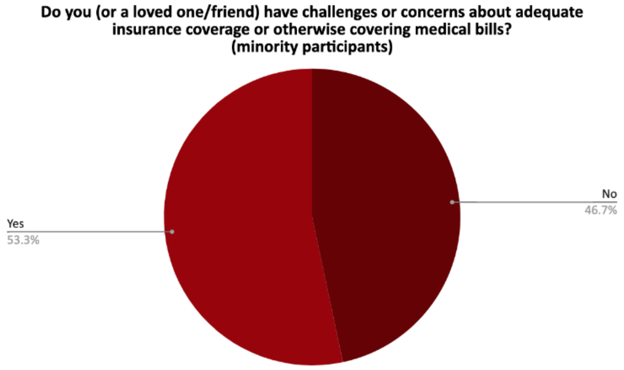
Insurance Coverage Challenges by Race

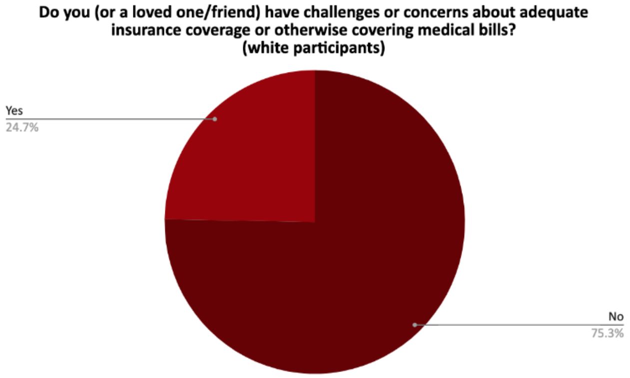
Research suggests that there are major gaps in the types of coverage held by whites, Blacks, and Hispanics among people with health insurance. Private insurance is much more common among whites than among nonwhites, while public insurance is more common among Blacks and Hispanics. Our survey supports these findings when comparing insurance challenges and concerns of minority survey participants (top graph) with that of white participants (second graph). Our results show that as you shift from minority participants to non-minority participants, the concern for insurance coverage is not as much of a factor for non-minority participants.

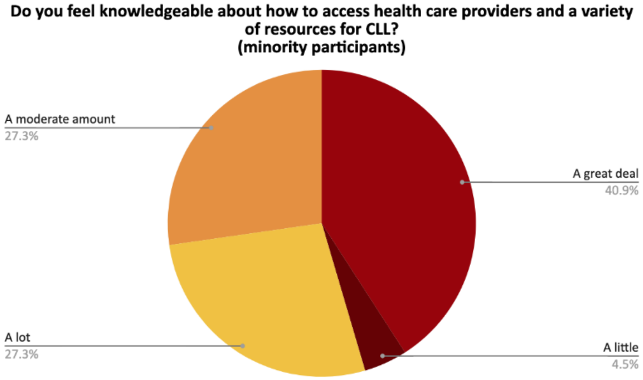
Access to Healthcare Providers by Race

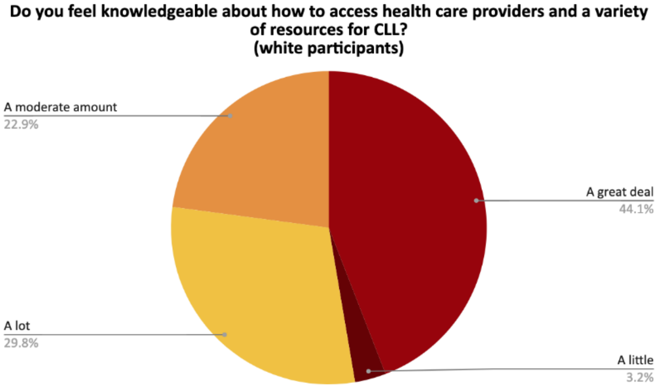
Access to healthcare can also be hampered by a lack of health literacy. A patient's ability to interpret health information and recommendations from their healthcare services is influenced by their health literacy. This is particularly troubling in rural areas, where inhabitants also have lower educational standards and a higher rate of poverty. Residents with low health literacy may be unable to pursue medical help because they are afraid of or frustrated by engaging with a healthcare provider. Furthermore, without health literacy skills, accessing the healthcare system can be challenging.

The results from our survey show the disparities across health literacy based on race, confirming the theory that minorities face barriers based on knowledge and education more than non-minorities. The graph second to the bottom shows minority participant responses, while the bottom graph shows non-minority participant







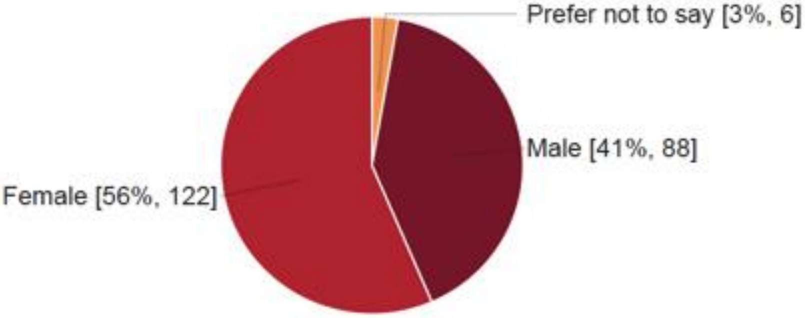


responses. The major takeaway is that white participants feel more knowledgeable overall about access to healthcare providers and resources. This barrier contributes to the disparities that exist within CLL Society's outreach initiatives and healthcare overall.

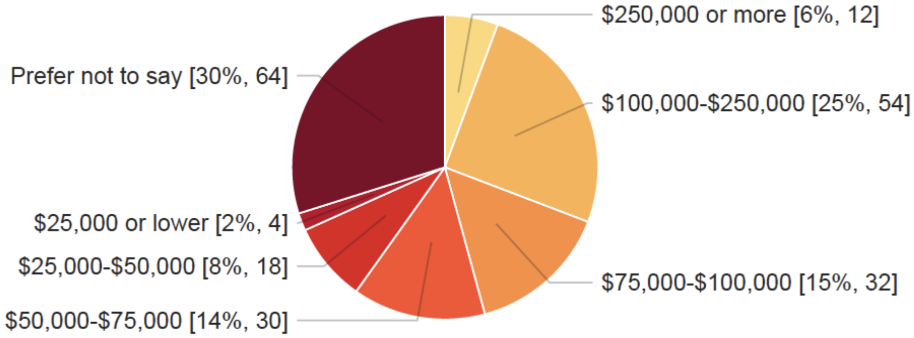
Demographics: Who are the Respondents?

The following graphs represent the income levels, age, gender, and race of the respondents:

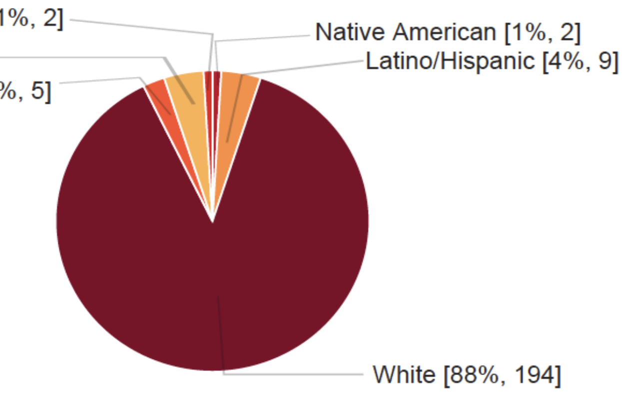
GENDER IDENTITY DEMOGRAPHICS



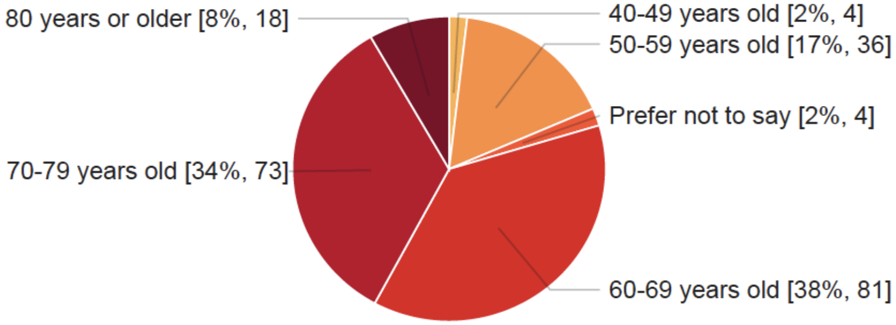
INCOME LEVEL DEMOGRAPHICS



RACIAL AND ETHNIC DEMOGRAPHICS



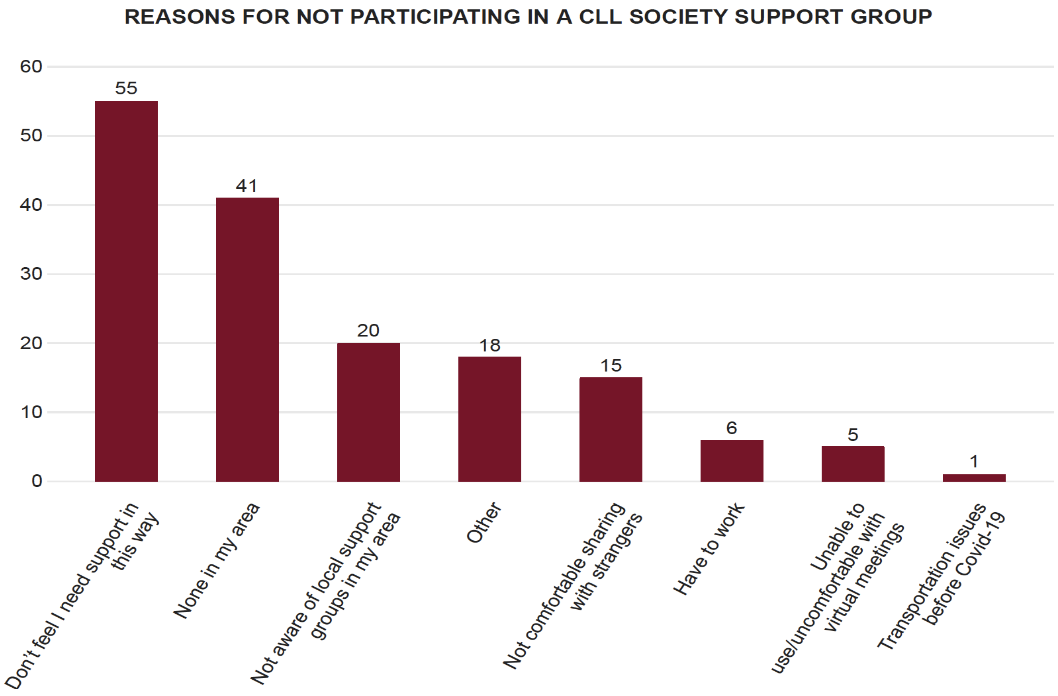
AGE DEMOGRAPHICS



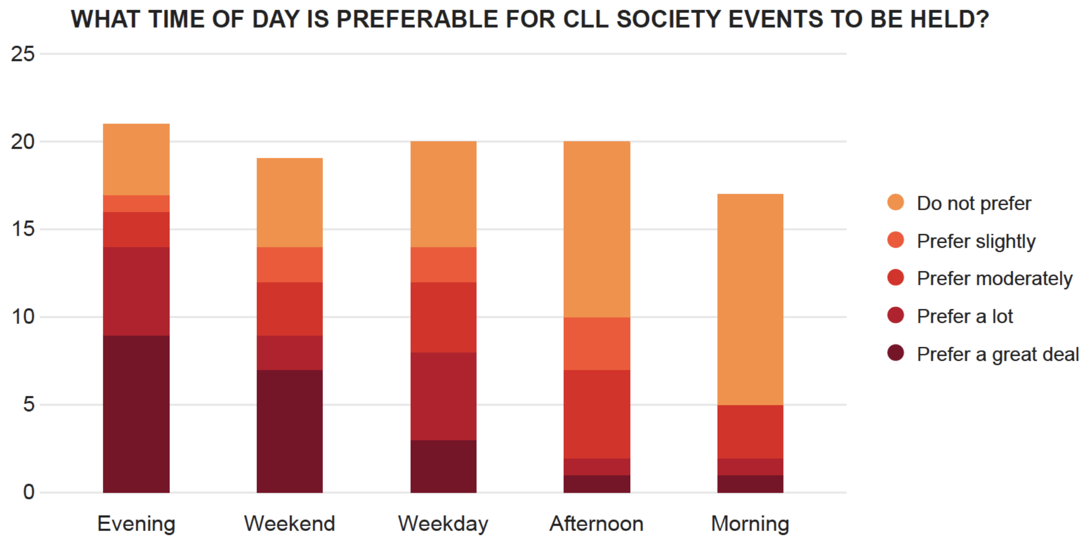
Assessment of Barriers and Needs/ Disparities

Many health-care services in the United States are aimed at a seemingly homogeneous group of people, usually financially stable whites.[124] Groups such as minorities or elderly patients face barriers to access more than their non-minority counterparts, which can ultimately put their health at risk. Based on our research and survey results found below, we have identified barriers and needs that currently exist in this context, which will be expanded on in later sections.

As shown in the graph below, location alone can be a barrier for those who live in rural areas. Our results show that 41 survey respondents do not participate in CLL support groups because there are not any in their area.



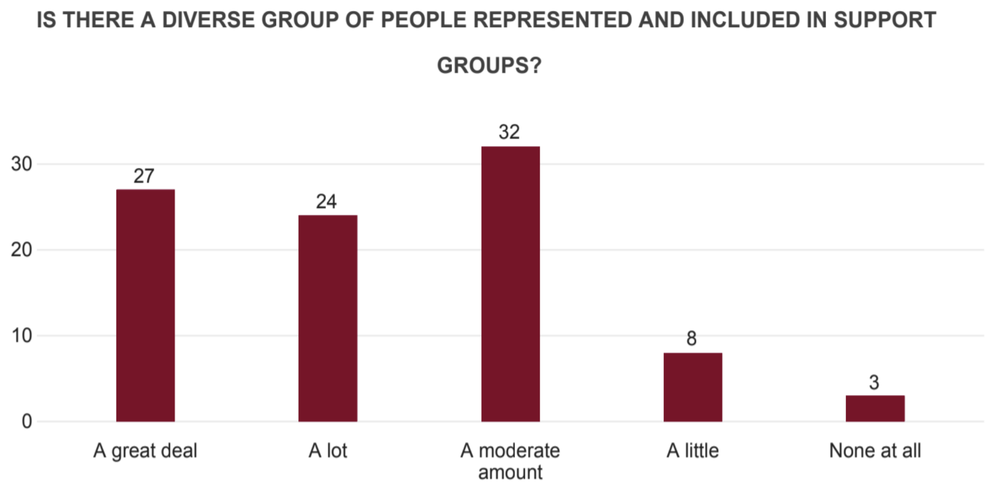
Another barrier to successful community outreach for CLL could be based on types of events or time of day that events will be held. As shown below, most respondents prefer for CLL Society events to be held during evenings and weekends. Ensuring that outreach events and education forums take place when people are free, rather than at work, and nearby, rather than far away, can increase engagement and effectiveness.



Future studies should look at ways to overcome the barriers that have been found, as well as ways to improve equitability. For example, specialized educational programs (such as cultural training) for healthcare professionals should be included when considering outreach strategies. Health providers may also be mindful that due to healthcare delivery and access barriers, a framework that is not tailored properly to fulfill client needs can influence patients' ability to take care of their own health.

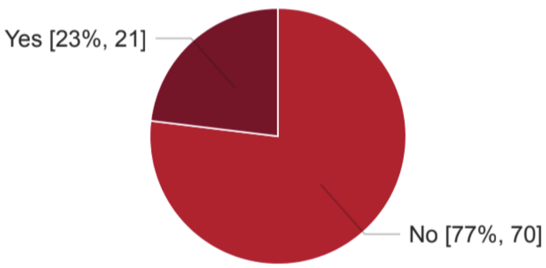
Priority Populations for Assistance/ Support

As shown by our survey results, a decent portion of the respondents who participate in a CLL Society Support Group appear to be on the fence about the level of inclusion there is of diverse individuals in support groups. Although only 11 people answered “a little” or “none at all” to the question about inclusion in support groups, their recognition of the lack of diversity should not be discounted. This response indicates CLL Society still has room to improve in inclusivity. Furthermore, in recognition that most of the respondents who took the survey identified as white, minority groups not represented and included in support groups may not be captured by our survey.

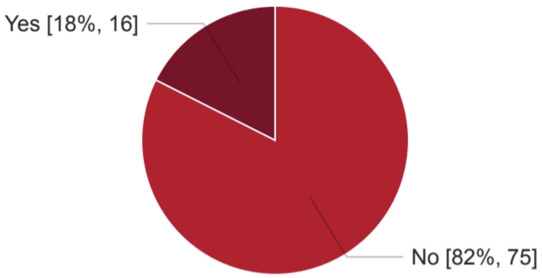


We know that there are certain populations and areas that are in need more support than others. Although represented by only 23% of respondents on the survey results, our survey still indicates individuals feel there are opinions and concerns of people that are left out in CLL Society Support Groups.

ARE THERE PEOPLE IN CLL SOCIETY SUPPORT GROUPS WHOSE OPINIONS AND CONCERNS ARE NOT RECOGNIZED?



ARE THERE PEOPLE NOT ADEQUATELY REPRESENTED IN CLL SOCIETY SUPPORT GROUPS?



Additionally, the table below depicts multiple comments signifying various topics that are lacking, racial diversity being the most prevalent. Being intentional about expanding to reach individuals beyond CLL Society's current network is crucial for diversity's sake, as will be discussed in the following sections.

Do you feel there are people who are not adequately represented in your group? If yes, please share your observations.

Topic	**Comment**
Race	Racial and ethnic populations.
Race; age	Most of the people seem to be older and not BIPOC.
Age	Adults below age 65 (outside of the typical age range of diagnosis)
Internet access	The meetings are virtual during the COVID restrictions so any persons without an internet connect would not be able to participate easily.
Internet comfort	People who are not comfortable w Zoom
Race	All Caucasian

Race; stage of disease	Few people of color; few people who've had several treatments
Stage of disease	Everyone in the small support group has either a 13q or 11q deletion and are mutated. To my knowledge, there is no one with both and no one unmutated. There are no 17p or p53. I am unmutated, so I see that lack. If anyone joins who has 17p or p53, they will have no cohorts.
Race; socioeconomic	Poor, POC seem to be missing
Race	This group which I now attend sporadically is weak in its presentations. There are not a lot of diverse individuals represented which may be more of an indication of the people with CLL in the area.
Race; gender; age	We are all white, about 50% by sex, and mainly retirement age.

In recognition of existing opportunities for CLL Society to expand to serve more diverse populations, we consider what makes these groups more vulnerable or in need of increased support. Correspondingly, we provide strategies CLL Society should initiate for reaching various populations currently underrepresented and underserved by the organization in the following sections.

Black & Latinx Community Outreach

The results of our survey indicate a lack of reach into Black communities, alongside limited reach to Latinx and other underserved communities, helping to confirm the CLL Society's need for outreach measures in these directions. A focus on Black and Latinx community outreach strategies for health promotion and disease awareness reveals four intersecting avenues of access—Black churches, Black barber shops, Latinx community health centers, and Community Health Workers, or *Promotores de Salud*.

Avenues of Access

Two primary avenues into the Black community have long been recognized in health care and health education initiatives: Black churches and Black barber shops. Although currently less studied and standardized, strategies of outreach to the Latinx population follow a third important avenue: localized community healthcare centers. Both Black and Latinx communities rely heavily on community health workers (CHWs, or *Promotores de salud*), a crucial fourth avenue that interconnects with the other three. Many of the establishments, institutions, and individuals along these four avenues participate in national networks that promote health services and education, or that have healthcare incorporated into their wider mission.

Black Churches

In the 1980s and early 1990s, Black churches were identified as potentially effective settings for health promotion[125] and have since developed into key venues for promoting health education to the Black community. As of 2014, an estimated 80% of the Black population of the U.S. —around 30 million adults—attend church with some regularity.[126] Long a center of Black spiritual, political, and social life, the Black church is one of the most prominent and credible institutions in the Black community nationwide, and members' health and wellness is often articulated as part of the church mission.

Partnership with Black churches can therefore substantially improve the credibility of healthcare organizations and initiatives, helping to mitigate long embedded distrust of public health and medical programs among Black Americans.[127] Over the past four decades, by partnering with hospitals, local and state health departments, professional associations and health-focused nonprofit organizations, Black churches have offered many various services and educational programs with notable success. These offerings have included programs for hypertension, cardiovascular disease, and diabetes management and prevention; exercise, weight loss, and cholesterol reduction; smoking cessation; health and wellness; screenings for heart disease, prostate cancer, breast, and cervical cancers; and education about other chronic diseases and health concerns significant to the Black population.[128,129]

Black churches have the potential to provide the deepest and broadest reach into the Black community, with the important benefit of legitimating medical initiatives through association with spiritual leadership. There are limitations, however. While church attendance skews older and therefore aligns with the typical age group for CLL diagnosis, most frequent and regular churchgoers are women, and may not include the most vulnerable, instead skewing towards those more attuned to self-help and better habits.[130] Outreach through Black churches should therefore be done in tandem with efforts in other directions.

Black Barber Shops

Another vital setting that has been successfully utilized in health promotion is the neighborhood barbershop, a well-known cultural and community forum for Black men. Barbers are commonly positioned as respected and effective community leaders, creating an atmosphere for relationship and trust building, open discourse, and vulnerability among men of different generations within the safe space of the shop. Black barber shops thus represent a network of community safe-spaces where a high-risk and otherwise difficult-to-reach group—Black men—can be identified and engaged in an efficient, cost-effective manner.[131]

The success and ubiquity of barbershop health programs over the past two decades have shown that Black barber shops can be ideal venues for connecting Black men to health information and encouraging health-related behavior, by “going to places that Black men frequent” and where many may go more readily than a doctor’s office or clinic.[132] These initiatives have been localized, state-wide, or nationally networked through health collectives and disease-focused nonprofit organizations in collaboration with medical centers, universities, and the Centers for Disease Control’s Comprehensive Cancer Controls Center.[133] Programs have focused on awareness, education, and early detection of prostate cancer, colorectal cancer, hypertension, and cardiovascular disease, and many train barbers as CHWs, enabling them to dialogue about a range of other disease areas such as diabetes and various cancers.

Outreach targeting barber shops enables focus on diseases and health concerns that predominate among men, broadening access to members of the community who may not be reached in the church setting. Drawbacks to the barbershop setting may include the fact that individual shops can be highly localized (the flipside of being deeply embedded in a community), possibly drawing men of a specific cultural orientation, and missing men who do not go to the barber for other reasons (such as baldness, self-grooming, or feeling sexually marginalized).[134]

Latinx Community Health Centers

In context of the diversity that exists under the umbrella terms “Latinx” and “Hispanic,” Latinx communities are considerably less culturally unified, but are aligned with the Black community in being faith-based, family-centered, and with strong ties to the neighborhood. Yet, although Latino churches exhibit many of the characteristics conducive to successful faith-based health promotion[135] and a limited number of initiatives have demonstrated effectiveness over the last decade,[136] there is a notable dearth of such programs and no significant network or overarching organization has developed to this point. Barbershop-type initiatives are even more absent in the landscape of Latinx health promotion.

On the other hand, scores of Latinx health centers and other health-related nonprofit organizations collaborate in city-wide, regional, and national networks dedicated to delivering bilingual, culturally competent healthcare and health education to members of diverse Latinx communities. Many networks and individual centers prioritize providing services regardless of immigration or insurance status or ability to pay, coordinating with healthcare providers willing to treat patients with these needs.[137] In addition to comprehensive primary care, centers focus on health and wellness programs; chronic disease maintenance (specifically diabetes, obesity, and hypertension); community benefits counseling; and promoting education and awareness of a range of health issues and diseases. Core to the mission of many networks and centers is training community members as *Promotores de salud*, a practice which helps to strengthen ties to the neighborhood and increase trust in medical services and health providers in context of often radically different sets of health beliefs and customs of self-treating.[138]

Community Health Workers / Promotores de Salud

Community health workers (CHWs)—in Spanish, *Promotores de salud*—are lay members of the community who serve as intermediaries between the community and local health care providers, working either for pay or as volunteers. CHWs ensure thorough cultural competence, interpret, and translate between patients and providers, give informal guidance and counseling, advocate for individual and community needs, and deliver culturally appropriate health education and a limited number of care services. Perhaps most importantly, because CHWs are uniquely positioned to liaise between providers and communities, they aid in effective mitigation of longstanding concerns held by both Black and Latinx populations about institutionalized healthcare.[139]

Many health promotion initiatives and healthcare network organizations incorporate CHW training into their outreach and education strategies, including church, barbershop, and community health center programs.[140, 141] Black churches have been doing so for almost four decades, training church members to conduct health programs for fellow members and the wider community,[142] and many Latinx health center networks make CHW and *Promotores* training a central part of their mission.[143] The Centers for Disease Control provides a comprehensive guide to integrating CHWs into community health programs focused on chronic disease. *Addressing Chronic Disease through Community Health Workers: A Policy and Systems-Level Approach*[144] offers program descriptions, policy recommendations for sustainability, and state health department resource listings, demonstrating that CHWs are core to the success of healthcare outreach to underserved populations. Absent the direct development of a CLL awareness and education program in specific locations, coordination with CHWs is possible either through partnership with organizations (churches, barbershops, or others) already engaging their services, or through CHW and public health advocacy groups that share resources with members nationwide.

Core Principles

Black churches, Black barber shops, and Latinx community health centers have proven to be effective venues for health promotion outreach, and the integration of community health workers into a program ensures a higher level of engagement from the community, contributing significantly to program success. Each of these four avenues can be accessed through national network associations or initiatives that share the goals of disease awareness, education, and support that motivate the CLL Society.

Outreach efforts along the four avenues should be informed by three core principles for collaboration, which derive from the decades-long experience, challenges, and successes of health promotion initiatives in underserved communities:

1. **Cultural competence**, including religious competence, and recognition of embedded distrust of medical institutions for reasons of historical precedent and cultural difference
2. **Community involvement**, including community leadership and member-volunteers, and systematic solicitation of community feedback
3. **Sustainable commitment**, including consistent access to information and programs, plans for long-term funding and program design.

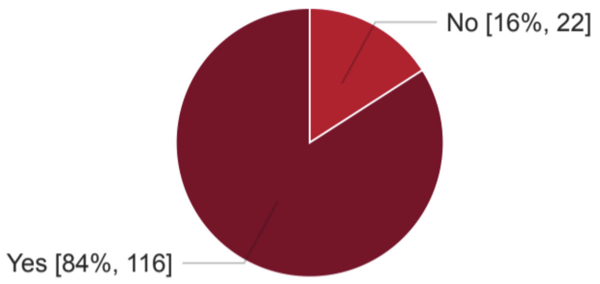
Entry into underserved communities of color must be gained by means of existing social networks and established relationships of trust, and by overcoming primary barriers of cultural and language differences. Cultural competence and, particularly in the case of Latinx communities, bilingualism is fundamental to successful, sustainable outreach efforts. Because such communities face numerous obstacles, including lower levels of education and income, limited health literacy, and lack of access to care or insurance, effective outreach should aim to coordinate affordable or free services, present specialized information in lay terms, and assist in obtaining care and navigating insurance requirements. Partnerships with local organizations and businesses can emphasize a sense of community involvement and trust by involving community leaders and members in planning and delivery of localized programs, tapping them as volunteers or workers where possible, and by actively seeking feedback from the community prior to, during, and following any program or event. Staff and providers should be ethnically and racially matched as possible, and thoroughly trained in cultural competence. Finally, outreach efforts should be planned for the long term rather than organized as isolated drop-in/drop-out efforts. A commitment to a community is essential to earning trust and furthering the goals of the outreach and should be considered both in funding and resource-gathering stages and in the design and development of any program.

Further, these core principles and many of the lessons learned along the four avenues of access can be adapted across racial, ethnic, and socioeconomic lines, keeping in mind sometimes critical differences in health concerns, belief systems, interests, and cultural sensitivities among marginalized groups.[145]

Elderly Community Outreach

The wellbeing of the elderly can be more impacted by their communities and neighborhoods due to different barriers such as reduced mobility. In the broader sense of social determinants of elderly wellbeing, community outreach, support, and education are a critical factor.[146] Community-based social service networks can help the elderly feel less alone, offer moral support, and gain more flexibility, all of which can improve their well-being and overall quality of life. The geographic accessibility of health care services is an important factor affecting elderly social engagement. Community events that are easily accessible provide the elderly with social service networks, improving mental health and general well-being. As shown below, 84% of respondents who were not already involved in a CLL Society support group said that being part of a community of people with CLL would be beneficial.

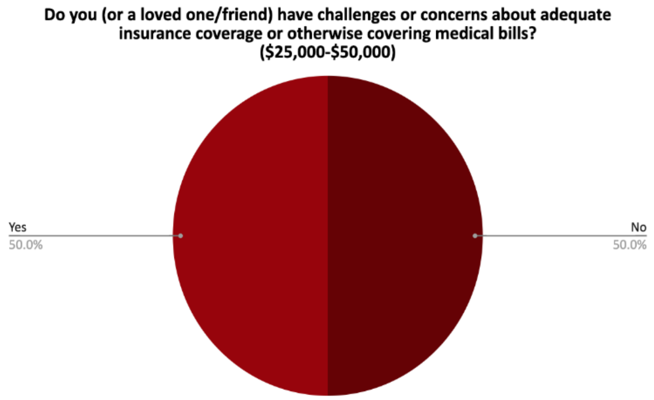
DO YOU FEEL BEING A PART OF A COMMUNITY OF PEOPLE WITH CLL WOULD BE BENEFICIAL?



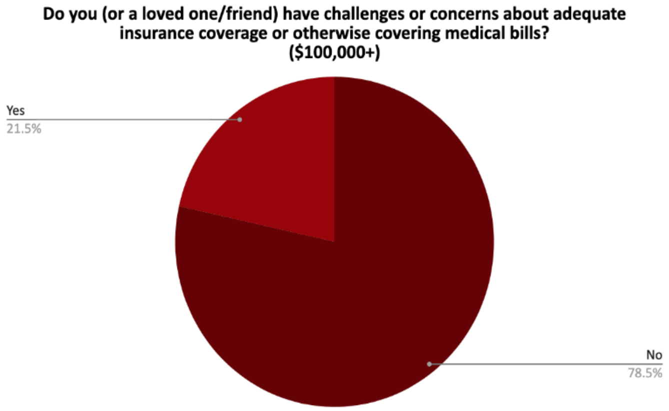
The elderly's ability to create and sustain social networks is heavily influenced by spatial factors, especially interactions between walkability, population density, and social cohesion. As a result, increasing elderly people's education, accessibility, and awareness through their ability to engage in community life necessitates outreach strategies that consider how neighborhood and individual variables intersect.[147] For elderly patients, a functional community outreach strategy should provide health promoting events and social service programs in a way that makes it easy for this demographic to participate. Community outreach programs encourage older people to participate in group events and communicate with one another, resulting in increased life satisfaction because of their social support networks.

Low Income & Rural Community Outreach

Access to healthcare and education is essential for good health, but low-income and rural communities face many obstacles. Rural residents frequently face healthcare barriers that hinder their access to receive the services, support, and education that they need. Our survey results in the graphs below show that as income levels increase, there is less concern or challenge to accessing adequate insurance coverage.


Do you (or a loved one/friend) have challenges or concerns about adequate insurance coverage or otherwise covering medical bills? ($25,000-$50,000)

Rural residents must have adequate access to essential and suitable healthcare facilities, which must be affordable and accessible in a timely manner.[148] And if the city has a sufficient availability of healthcare facilities, there are other considerations to weigh in terms of accessibility. To have diverse, equitable, and inclusive healthcare services and education, rural and low-income communities must also have:


Do you (or a loved one/friend) have challenges or concerns about adequate insurance coverage or otherwise covering medical bills? ($100,000+)

- Belief that they will receive high-quality, fair treatment
- Esteem in their ability to interact with healthcare professionals, particularly if they do not speak English fluently or have low health literacy
- Access and transportation to healthcare, education, and support facilities, as well as the ability to receive paid time away from work to use those services
- Financial resources, such as health or dental insurance approved by the insurer, to pay for care
- Confidence that they will be able to access programs, support, and resources without jeopardizing their privacy

The closing of rural healthcare facilities or the discontinuation of coverage can have a detrimental effect on a rural community's access to healthcare. Local rural healthcare services are vulnerable; as one hospital closes or a provider exits, it can have a ripple effect on care and access in the region.[149] Patients are burdened by having to travel to access healthcare treatment. Individuals with reduced earnings, no paid days off from work, physical disabilities, acute illnesses, or no personal transportation face serious challenges in accessing healthcare facilities. Rural communities are creating outreach and wellness initiatives that use curricula, resources, and media to raise community members' healthcare education and awareness. The research shows that some outreach and inclusion strategies are more effective than others when it comes to this demographic. Adjusting delivery models and strategies is critical when trying to be inclusive of this population. Meeting families at local sites such as libraries, schools, laundromats, and supermarkets, as well as engaging in local festivals and fairs, will help them gain access to healthcare resources and education when they are out running errands and doing their normal daily routine.[150] Building partnerships with groups with strong links to the neighborhood will also serve to boost enrollment and education. The challenges that rural residents face in accessing healthcare services and contribute to health disparities. To form a more well-rounded healthcare system, community outreach efforts must focus on providing education and resources to those who have the hardest time accessing it.

Family/ Spouse Support & Community Outreach

Collecting and reviewing data with the goal of recognizing households and families that have not been reached and exchanging accurate knowledge locally and with neighborhood members is one facet of effective outreach. Reaching out to families we have not been able to reach because we lack the necessary expertise, skills, or language allows us to consider what makes resources difficult for families to recognize or use.[151] Effectiveness will be improved by moving away from presenting information to families and toward listening to them—and reacting to their actions, attitudes, and concerns.[152] Below are some examples of ways to be inclusive of families through CLL Society outreach and education methods:

- Hold community events that allow families to connect with each other
    - Examples: picnics at parks, guest speakers, celebrities to draw attention to the event
    - A positive experience that people can look forward to and bring their families to will likely increase participation
- During adult-focused events, provide activities for kids so that parents can bring their children if they must, but are still able to meet and chat and get support
- Allow family members that act as support systems/ caretakers to provide input on needs/wants through post-event surveys/ interviews

General Outreach Strategies & Characteristics

CLL Society must work with other organizations to educate community members in their service area about CLL prevention and early detection by providing educational presentations and training and distributing information at community events. The focus of community education and awareness is community members (i.e., outside of a health system or clinic setting), particularly those in the priority (underserved/ in need) populations. Characteristics of a diverse, equitable, and inclusive education and outreach strategy include:

- Involvement and participation of the target group

- Evaluation of community needs to determine community ability, finances, goals, and needs
- Scheduled learning opportunities to improve participants' awareness and skills
- Delivery of services with integrated, well-planned curricula and materials in an environment that is suitable for participants

As mentioned throughout this report, many community members face barriers when trying to access healthcare education. As a result, using online or virtual methods to engage with and educate the community can be very effective. Examples of potential health education activities include workshops, e-learning class, online lectures, webinars, and virtual meetings. The results from our survey show that over 90% of survey participants would be interested in attending education lectures and online events. This means that the want for these activities is already present, and CLL Society should work to utilize that interest and expand its reach. Additionally, the following outreach strategies have shown to be effective overtime. Many but not all points in this list are adapted from outreach strategies of the highly reputed Men of Color Health Awareness (MOCHA) program centered in Springfield, Massachusetts.[153]

- Direct mail solicitations (culturally tailored)
- Public service announcements on radio/television (local stations, culturally matched)
- Newspaper ads
- Social media promotion (generation-appropriate – Facebook, not Tumblr)
- Posters on health center bulletin boards and social service agencies
- Flyers/brochures in targeted settings or distributed by community volunteers
- Tabling at culturally specific events (Jazz Festival, Juneteenth Celebration, etc.) and health fairs
- Incentives and giveaways for participation (culturally, generationally, economically appropriate: discounted haircuts, food, free services, branded tote bags)
- Ensure any face-to-face is with racially/ethnically matched staff or volunteers
- Collaborate with community-based organizations and businesses on any local events
- Use trained volunteers from the community at any local events, and to spread the word ahead of events

Recommendations

Our primary recommendation to the CLL Society is to approach a national CLL awareness and education campaign through select partnerships along each of the four avenues of access, giving the CLL Society broad reach into underprivileged communities nationwide. We advise you to:

Recommendation #1: Partner with recognized organizations with established inroads into communities, health-specific missions, and national networks.

Chosen partners should align with the principles of cultural competence, community involvement, and sustainable commitment in day-to-day practice, with demonstrated results and positive community feedback. Partners should engage and/or train CHWs to ensure cultural competence, have racially/ethnically matched staff or train staff accordingly.

Optimal partners will have similar chronic disease awareness and education in place that may accommodate the addition of CLL to their agenda, such as the National Black Church Initiative's Myeloma Link Program (a partnership with the Leukemia & Lymphoma Society), the Prostate Net's BarberShop Initiative (a partnership with the CDC's National Comprehensive Cancer Control Program), and *Redes En Acción*'s National Cancer Institute-funded focus on acute lymphocytic leukemia (see **Suggested Partnerships**).

Recommendation #2: Partner with CHW associations to access community health workers nationwide to ensure they are informed about CLL and the resources of the CLL Society.

Direct engagement with national CHW advocacy networks can put CLL on the immediate radar of CHWs who work with older adults in underserved communities, whether these health workers are involved in specific CLL Society outreach initiatives in their communities. Provide all resources and information about CLL in English and Spanish, both resources for CHWs themselves and those that they can distribute in the communities they serve. These resources could include webpages and printed brochures.

Recommendation #3: Train CLL Society staff that will be interfacing with outreach initiatives in cultural sensitivity.

Staff members that will interface with partner organizations or communities at any stage of development or implementation should receive training. Particular attention should be paid to differences among subgroups, including the differing beliefs, values, and traditions of various denominations within the Black church, and the diverse cultures and countries of origin that comprise Latinx communities in the United States. Sensitivity to economic conditions, immigrant (including undocumented) status, and distrust of medical institutions and research should also be included in training.

Recommendation #4: Create referral lists for local providers that are culturally and economically appropriate.

Referrals lists should be prepared and available ahead of any program implementation and can be compiled in collaboration with hospitals and health centers, medical schools, and other local healthcare organizations. Designate providers who are culturally competent, racially, and ethnically matched to the community, and who are willing to see low-income patients on sliding-scale payments or for no fee, or who do not have insurance.

Recommendation #5: Create tailored educational materials and program options for use in a range of communities and initiatives.

Educational materials and programs should be culturally competent, with culturally specific graphics, images (racially and ethnically matched images of patients and providers, culturally appropriate products, and brands), and in-text references. All materials should use lay terminology, attend carefully to the level of health literacy needed to comprehend the text, and include visual aids alongside descriptions.

While it is essential to be accurate and relay the seriousness of CLL, it is equally important to include positive messages about cancer and chronic disease management in educational materials and be sensitive to negative messaging that could provoke fears and reduce participation. If the program or materials are being designed for church-based initiatives, collaborate with representatives from that denomination to incorporate spiritual and cultural context, and consider using spiritual references alongside lay biomedical discussions. Finally, test all materials and program design with feedback groups from representative communities, including leaders, members, cancer survivors, CHWs, and local health providers.

Conclusion

In conclusion, there are many obstacles to equity and inclusion in community outreach and education for underrepresented groups. According to the research, a renewed focus on inclusion and diversity in CLL community outreach and education is both relevant and timely. Considering the volume and complexity of identified barriers to participation, well-designed education and outreach initiatives using appropriate measures and procedures are urgently needed to identify key determinants of knowledge, ability, and support of participation. Cancer prevention, screening, and high-quality cancer treatment are all at risk for these under-represented populations. To correct this, obstacles to effective treatment and outcomes must be addressed at several levels, including interpersonal and structural barriers. A concerted effort is needed to improve patient and caregiver education, improve outreach and assistance, provide training and education, provide health care staff who are aware of and responsive to community needs, and promote constructive policy and institutional action.

Community Outreach: Community Partners

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

Partnerships focused specifically on prominent and nationally networked associations to identify ten organizations along the four Avenues of Access (Black churches, Black barbershops, Latinx health centers, and Community Health Workers).

National Black Church Initiative (NBCI)
Website: https://www.naltblackchurch.com/
Contact: Rev. Anthony Evans, President - Dcbci2002@gmail.com - (202) 744-0184
Myeloma Link Program (NBCI partnership with LLS)
Website: https://www.naltblackchurch.com/health/lls-program.html
LLS MLP contact: Abby Williams - abby.williams@lls.org - (914) 821-8815

A coalition of 34,000 Black and Latino churches across the United States working to eradicate racial disparities in a range of areas, most centrally in healthcare, the National Black Church Initiative aims to provide critical wellness information and education to members, congregants, churches, and the public through faith and sound health science. Their efforts are primarily achieved through partnerships with organizations and officials positioned to further these goals, and their reach into the Black community is estimated at some 26.7 million individuals. The NBCI is currently partnering with the **Leukemia & Lymphoma Society** on the **Myeloma Link Program** to increase access to education and treatment for myeloma in Black communities, including access to the support services of the LLS and enrollment in clinical trials. Given the goals alignment between this program and the CLL Society, a triangulation of partnerships between the NBCI and the LLS, and the LLS and the CLL Society might be a highly effective approach to Black community outreach.

The Prostate Net: BarberShop Initiative
Website: http://www.theprostatenet.org/barber.html
Facebook: https://www.facebook.com/The-Prostate-Net-201011209954034
Contact: Virgil Simons, Founder & President
Email: virgil@prostatenet.org

The Prostate Net is a nonprofit patient education and advocacy organization that makes available accessible information on disease and treatment decisions, while promoting disease risk awareness and early interdiction. Established in 2004 and today partnering with the **Centers for Disease Control's National Comprehensive Cancer Control Program** in 16 locations nationwide, the organization's **BarberShop Initiative** creates collaborations between local networks of barbers and medical centers to educate patrons on prostate cancer prevention, treatment, and supportive care, to increase screenings and clinical trial participation, and to train barbers as Community Health Workers. With an impressive record of bringing prostate cancer education to the Black community, its collaboration with the CDC's NCCCP, and a mission goal to disseminate information on other diseases that impact the community, The Prostate Net and its BarberShop Initiative could be an ideal partner for the CLL Society.

Community Outreach: Community Partners

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

Black Wellness 24/7
Website: https://www.blackwellness247.com
LinkedIn: https://www.linkedin.com/company/blackwellness247

Relevant programs under Black Wellness 24/7 umbrella:
Black Doctor 24/7: https://www.blackdoctor247.com/ (app in App Store)
Black Barbershop Health Outreach Program (BBHOP):https://www.blackbarbershop.org
Black Salon Health Initiative (BSHI): (in development)

Black Wellness 24/7 is an umbrella organization that addresses Black American health disparities from a variety of angles, with a focus on community centers. Their efforts "consist of various targeted health campaigns that integrate technology, cultural sensitivity and the aggregation of Black healthcare providers to improve health outcomes among Black Americans." Their original initiative, the **Black Barbershop Health Outreach Program**, has been a model for health promotion across the U.S., engaging barbershop patrons through education, empowerment and community capacity-building activities. A sister program focused on Black hair salons is under development.

Redes En Acción: The National Latino Cancer Research Network
Website: https://redesenaccion.com/latino-cancer
Facebook: https://www.facebook.com/SaludToday
Email: redesenaccion@uthscsa.edu

Headquartered at the Institute of Health Promotion Research at UT Health San Antonio, Redes En Acción (Networks in Action) is a **National Cancer Institute**-funded network of more than 2,000 community leaders, researchers, government health officials and public advocates focused on reducing and managing Latinx cancer through research, training, and education. REA works to promote awareness of cancer and resources in Latinx communities, with emphasis on acute lymphocytic leukemia (ALL) among other cancers. This organization could be a valuable partner with the CLL Society given its cancer-specific aims, awareness and educational focus, and ability to access Latinx communities from multiple angles.

Community Outreach: Community Partners

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

National Alliance for Hispanic Health (NAHH)
Website: https://www.healthyamericas.org
Facebook: https://www.facebook.com/healthyamericas
FB Messenger: m.me/healthyamericas

Founded in 1973 with an initial focus on mental health issues in the broader Latinx community, the National Alliance for Hispanic Health is today a leading science-based, community-driven health organization and one of the very few operating on a comprehensively national level. Community-based members provide services to more than 15 million Hispanics, and national partners to over 100 million Hispanics across the country every year. The NAHH has directly facilitated 42,000 one-to-on sessions on health insurance, the completion of over 33,000 CHIP and Medicaid applications, and over 100,000 health screenings, and aims to "close the gap" in "research, services and policy; scientific discovery and benefit for the individual; and community services and medical practice" (Our Mission, https://www.healthyamericas.org/our-vision-and-mission2)

Men of Color Health Awareness (MOCHA)
Website: http://mochaspringfield.org
Email: mochamovingforward@gmail.com

A program of the City of Springfield (Massachusetts) Health and Human Services Department, MOCHA is dedicated to improving the health and wellness of Black and Latino men. Highly renowned for its innovative and successful outreach and recruitment strategies, the 12-week MOCHA program aims to empower men of color to take an active role in their health care, including among its primary goals enabling men to "effectively manage chronic diseases and reduce emotional stress levels," and to "confront health disparities caused by racial and class discrimination poverty, and gender role strain." The strategies developed by MOCHA can be implemented in most mid-sized cities—a key target for outreach to communities of color. The majority of urban people in the U.S. live in midsized cities, where growth rates are the highest among cities of any size due to in-migration of people of color.

Community Outreach: Community Partners

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

Esperanza Health Centers
Website: https://www.esperanzachicago.org
Facebook: https://www.facebook.com/esperanzahealthcenters
Contact form: https://www.esperanzachicago.org/contact
Contacts:
Heidi Ortolaza-Alvear, AM, MPP
Vice President of Strategy and Business Development
Ricardo Cifuentes
President of External Affairs

Ranked in the top 3% of health centers in the nation for quality of care (HRSA), Esperanza Health Centers deliver bilingual, comprehensive primary care, behavioral health and wellness services to the Latinx community regardless of immigration status, insurance status, or ability to pay. EHC programs include the diabetes education group ¡Viviendo saludable, viviendo feliz!, community benefits counseling (Medicare, Medicaid, SNAP), immigration physicals, and Cefecito con Esperanza, a senior social group. Primarily focused on Chicago's Southwest side, the six EHC sites service a total of over 55,000 patients annually and is a leading example of balancing broad-reaching quality care on a community level.

Latino Healthcare Forum
Website: https://www.lhcf.org
Email: info@lhcf.org
https://www.lhcf.org/contact
Promo Salud program: https://www.lhcf.org/promo-salud

Initially created to provide information to the Austin Latino community about the Affordable Care Act, the Latino Healthcare Forum developed into a center for comprehensive, culturally competent healthcare information and services for the vulnerable Latinx population in the greater Austin area. The LHF aims to reach people outside of traditional health settings in places such as schools and work sites as well as in health care facilities to provide free counseling and education. Core to the LHF mission is their Promo Salud program, which trains members of the community to be Community Health Workers, or Promotores de Salud, which the LHF then seeks to integrate into community-based efforts to help educate about and prevent, when possible, chronic disease.

Community Outreach: Community Partners

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

National Association of Community Health Workers (NACHW)
Website: https://nachw.org
Partnership opportunity contact form:https://nachw.org/contact

The National Association of Community Health Workers is a nationwide organization for professionals on the front lines of public health. The primary function of the NACHW is to support and give a unified voice to community health workers (CHWs) through education and advocacy towards the interconnected goals of community health, equity, and social justice. The timing for a partnership may be optimal, as the NACHW is currently redeveloping its strategic plan to improve their ability to "strengthen the profession's capacity to promote healthy communities" (Our Mission, https://nachw.org/about/).

American Public Health Association (APHA)
Community Health Workers Section
Website:https://www.apha.org/apha-communities/member-sections/community-health-workers
Facebook: https://www.facebook.com/APHACHWSection/

Under the umbrella of the American Public Health Association, the Community Health Workers section advocates for the position and development of the CHW role (including Promotores de Salud) in public health and community healthcare settings. The CHW section maintains a nation-wide forum for sharing resources, activities and strategies, and participates in the APHA Annual Meeting and Expo, a highly visible networking and research presentation event.

Community Outreach: Internet Access

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

Partnerships group looked into organizations and platforms that can provide or connect users with resources to low-cost internet services. A common barrier to finding information and resources online, is having affordable internet services in their area and home. The below organizations provide resources on finding affordable internet services and how to obtain them.

EveryoneOn
Website: https://www.everyoneon.org/
Contact: support@everyoneon.org

EveryoneOn helps bring "low-cost internet and computer offers to those who need them." EveryoneOn does this through providing information on and low-cost resources for internet, priced between $10 to $20 per month, and digital literacy trainings. EveryoneOn has more than 650 enrollment partners who serve under-resourced people gain affordable internet access across the country. The Digital Equity Champions help increase access to low-cost internet services, affordable computers, and digital literacy resources just by sharing EveryoneOn's resources on their website.

Allconnect
Website: https://www.allconnect.com/
Contact: allconnectpartnerships@redadventure.com

Allconnect helps connect users to local internet and tv services for their homes through a quick, easy, and free questionnaire. Allconnect also offers resources for cheap internet, different providers, tools to determine a user's internet needs, and many guides and how-tos on how to find or use internet services. A great resource on Allconnect.com is their blog that includes not just information, but short quizzes for readers to learn more about their needs and what reliant and low-cost providers are near them

Community Outreach: Transportation

INDIANA UNIVERSITY O'NEILL CAPSTONE FOR CLL SOCIETY

Partnerships researched to find transportation companies that provide low-cost or free rides to assist people with getting out into the community. Lack of reliable, and affordable, transportation is a common barrier in accessing necessary resources like healthcare. The below resources are potential resources that can offer affordable or free transportation.

Ride United- available in select cities
Website: https://www.unitedway.org/our-impact/featured-programs/2-1-1/ride-united#Get-Support
Contact: Hilary Palotay, Hilary.Palotay@uww.unitedway.org

Ride United is a program supported by United Ways, 211, and other partners to address unmet transportation needs in communities everywhere. By dialing 211 or visiting 211.org, a 211 specialist can connect someone to the best available service near them. While not every community offers free transportation, more than 250,000 requests for transportation assistance are made each year and Ride United is helping close transportation gaps.

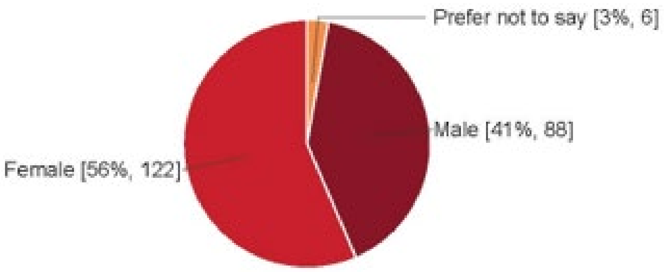
LyftUp Access Alliance
Website: https://www.lyft.com/lyftup/programs

Lyft's Access Alliance is addressing the barrier of inadequate transportation opportunities through partnerships with impact-driven organizations. The LyftUp Program is "providing access to the rides people need to get to critical resources and services" by offering transportation access programs to select locations. To access, a user needs to complete a registration form or filling out the online application to determine eligibility.

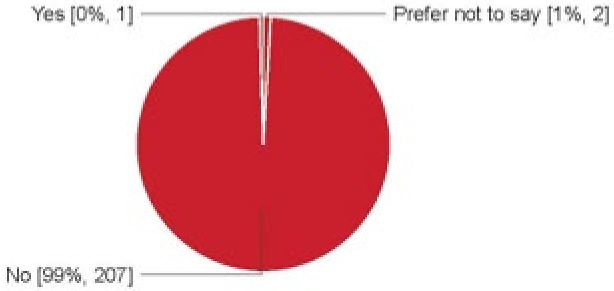
Appendix B: Community Outreach Survey Results

Demographics of Survey Respondents

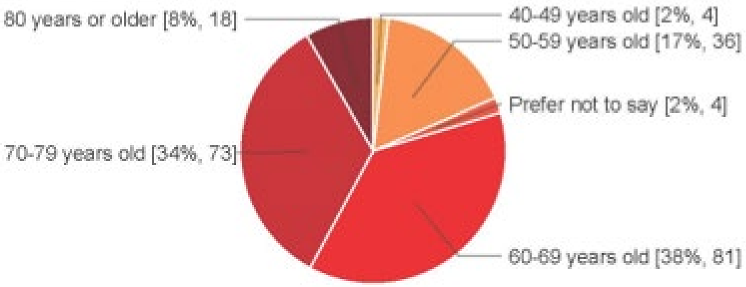
GENDER IDENTITY DEMOGRAPHICS



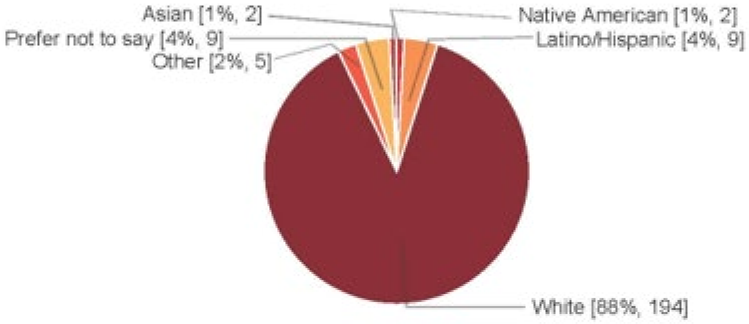
LGBTQ+ IDENTITY DEMOGRAPHICS



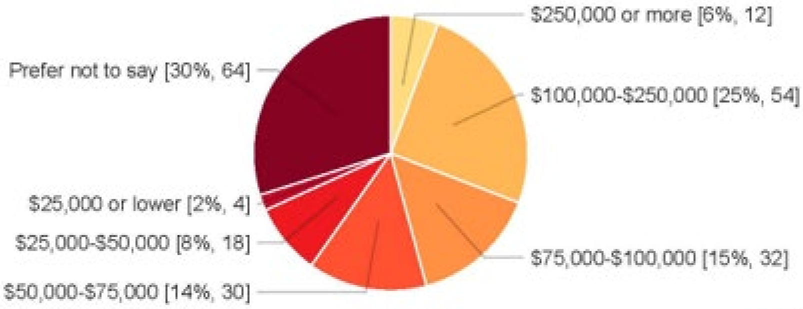
AGE DEMOGRAPHICS



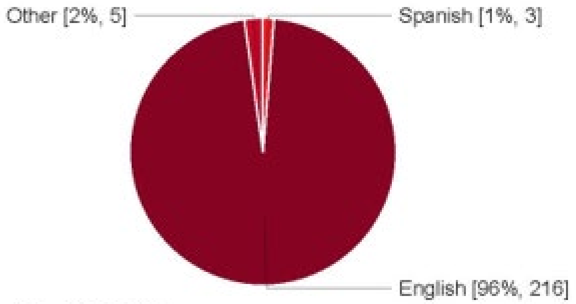
RACIAL AND ETHNIC DEMOGRAPHICS

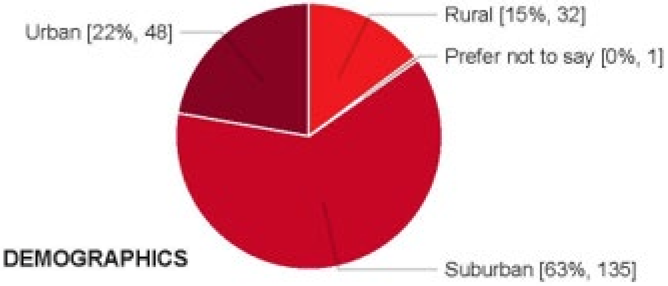


INCOME LEVEL DEMOGRAPHICS



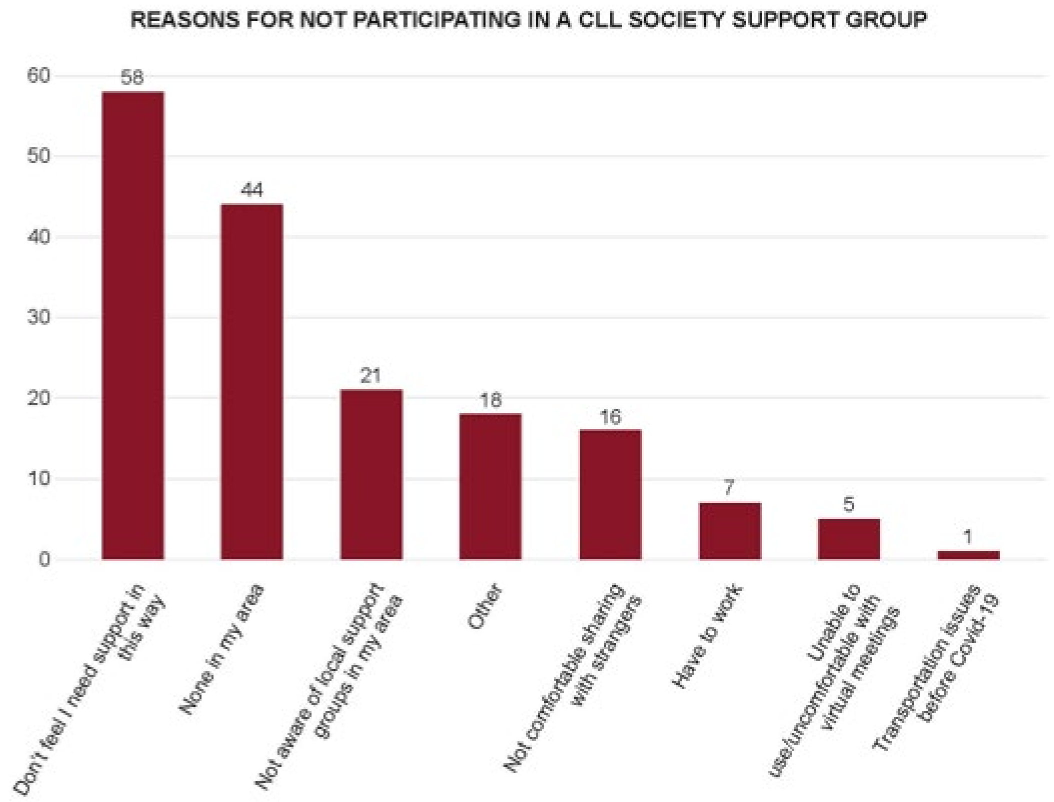
PRIMARY LANGUAGE DEMOGRAPHICS

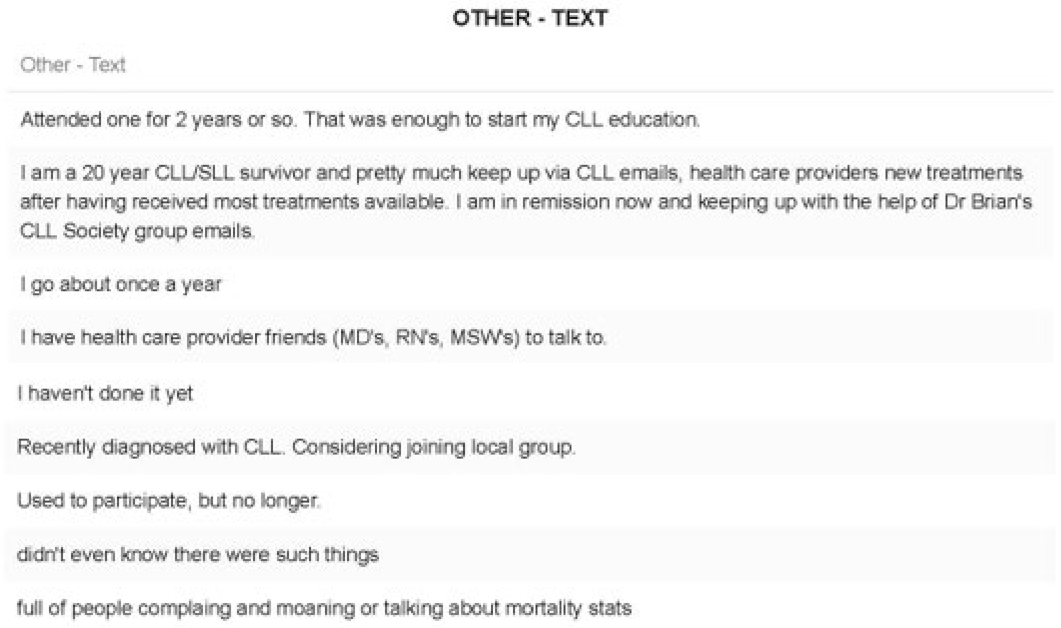




HOUSING AREA TYPE DEMOGRAPHICS

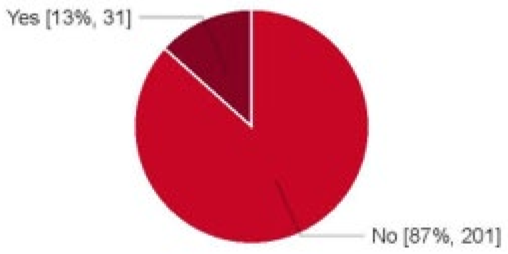
Barriers to Accessing CLL Society Programs


REASONS FOR NOT PARTICIPATING IN A CLL SOCIETY SUPPORT GROUP

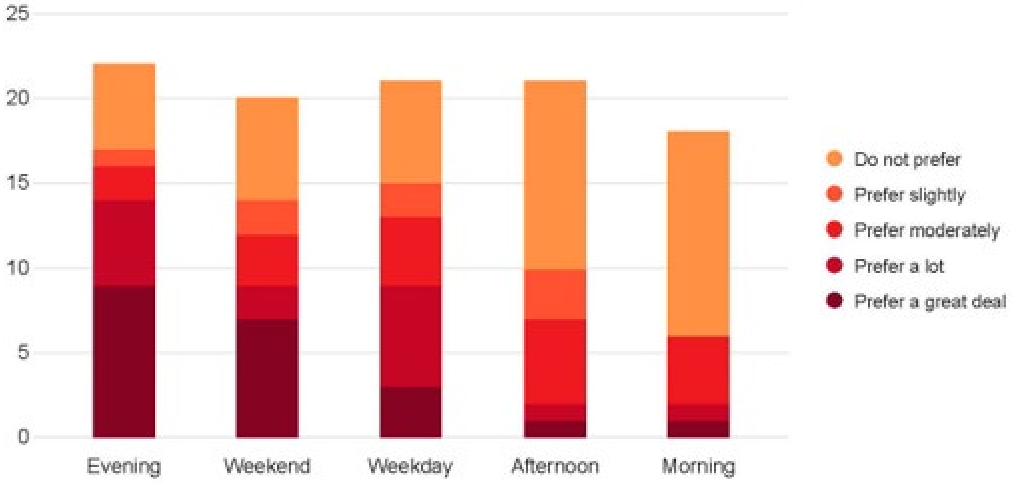

OTHER - TEXT

Other - Text
Attended one for 2 years or so. That was enough to start my CLL education.
I am a 20 year CLL/SLL survivor and pretty much keep up via CLL emails, health care providers new treatments after having received most treatments available. I am in remission now and keeping up with the help of Dr Brian's CLL Society group emails.
I go about once a year
I have health care provider friends (MD's, RN's, MSW's) to talk to.
I haven't done it yet
Recently diagnosed with CLL. Considering joining local group.
Used to participate, but no longer.
didn't even know there were such things
full of people complaing and moaning or talking about mortality stats

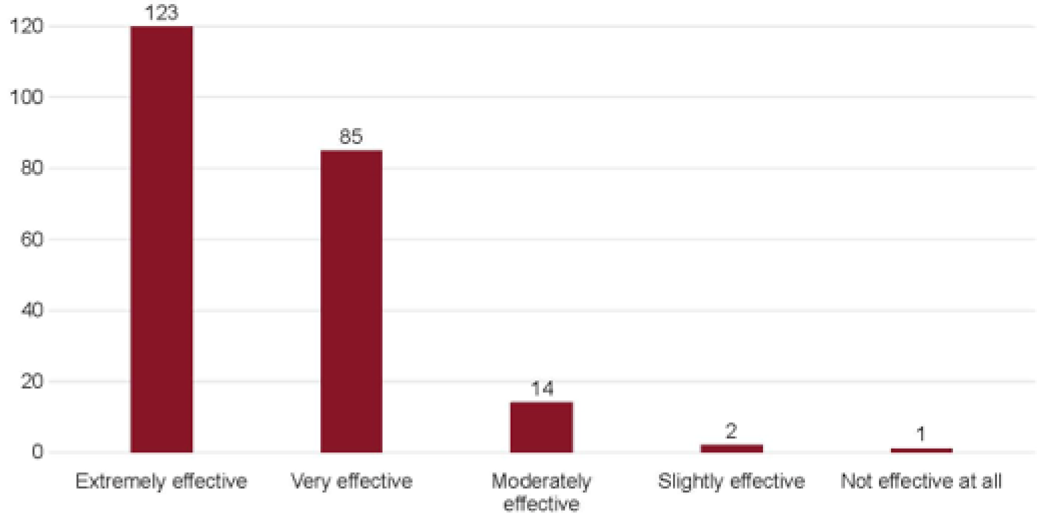
FAMILY AND/OR WORK REQUIREMENTS IMPACTING ABILITY TO PARTICIPATE IN CLL SOCIETY EVENTS



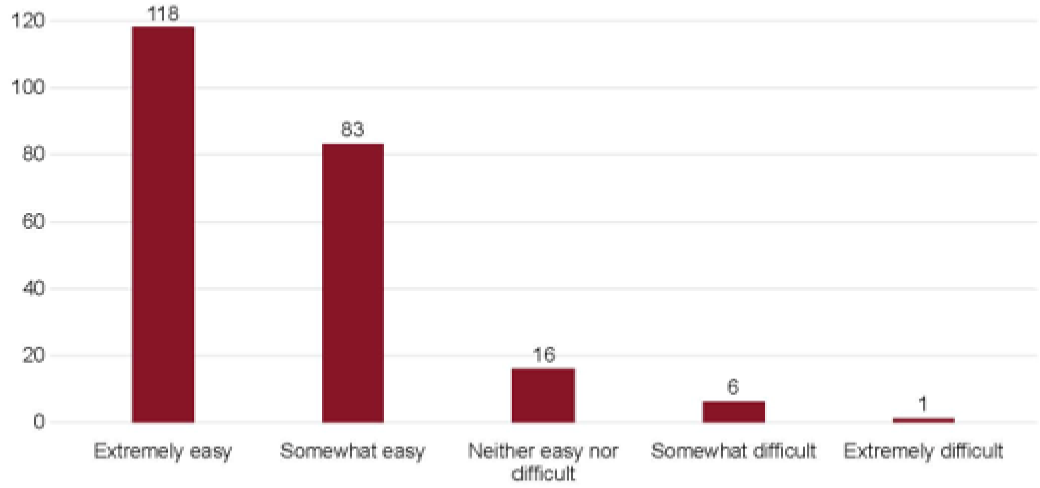
WHAT TIME OF DAY IS PREFERABLE FOR CLL SOCIETY EVENTS TO BE HELD?



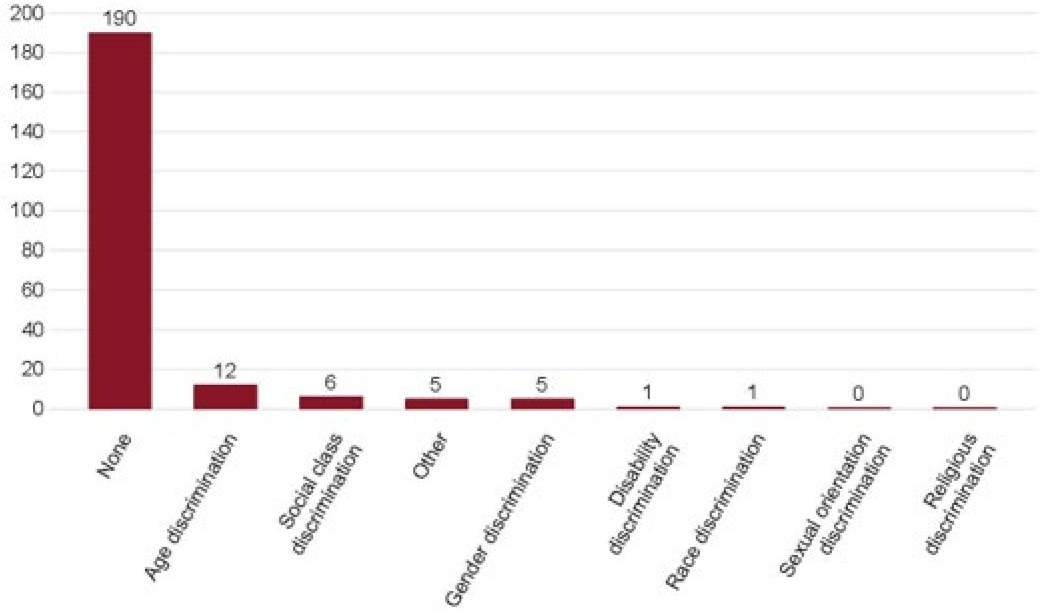
TO WHAT EXTENT DO YOU FEEL CLL SOCIETY RESOURCES ARE EFFECTIVE IN PROVIDING INFORMATION THAT IS REPRESENTATIVE OF YOUR IDENTITY AND CLL NEEDS?



HOW EASY TO NAVIGATE DO YOU FIND THE CLL SOCIETY WEBSITE TO BE FOR FINDING THE INFORMATION YOU ARE SEEKING?



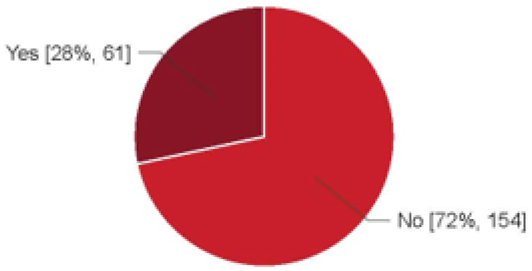
DISCRIMINATION-BASED BARRIERS TO ACCESSING QUALITY HEALTH CARE, OUTSIDE OF CLL SOCIETY



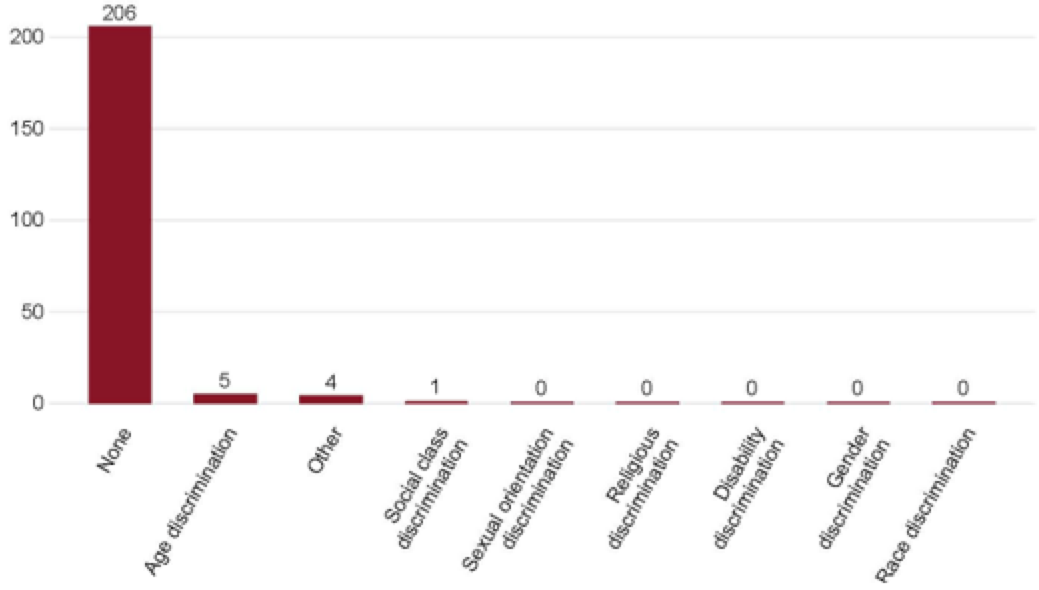
OTHER - TEXT

Other - Text
Financial levels (ability to pay)
I live in Hawaii, hard to find knowledgeable specialist here, impossible. So I have to travel, which is very stressful.
Smoker
not relevant question

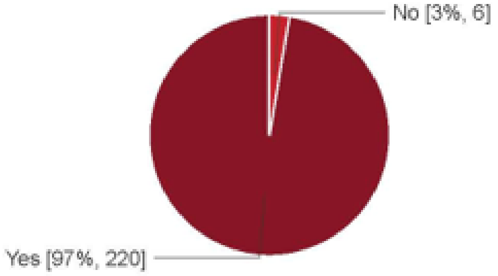
ARE THERE CONCERNS OR CHALLENGES AROUND HAVING ADEQUATE HEALTH INSURANCE COVERAGE OR OTHERWISE COVERING MEDICAL BILLS?

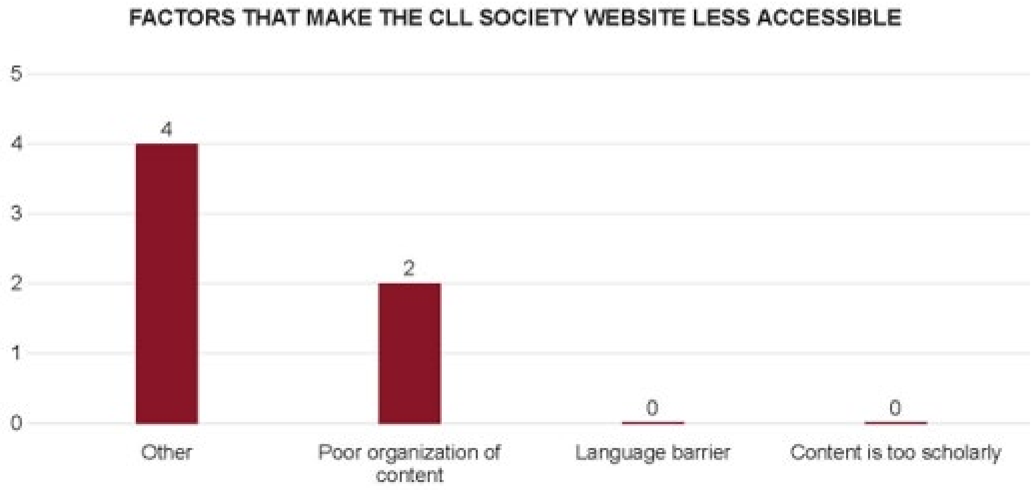


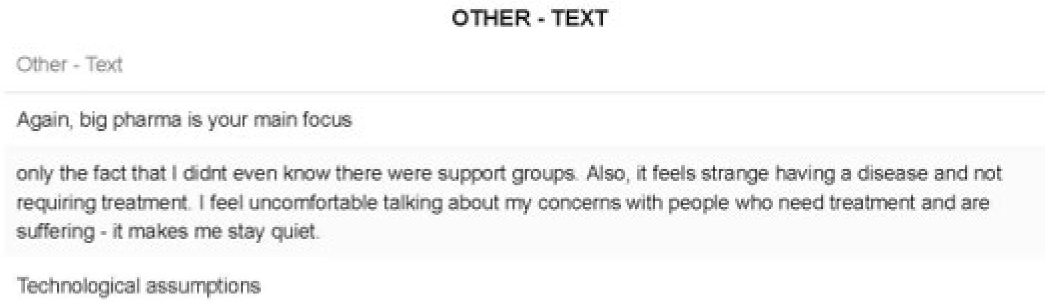
DISCRIMINATION-BASED BARRIERS TO ACCESSING QUALITY HEALTH CARE, WITHIN CLL SOCIETY



DO YOU FEEL THE CLL SOCIETY WEBSITE PROVIDES ADEQUATE AND ACCESSIBLE INFORMATION REGARDING CLL THAT FITS YOUR NEEDS?

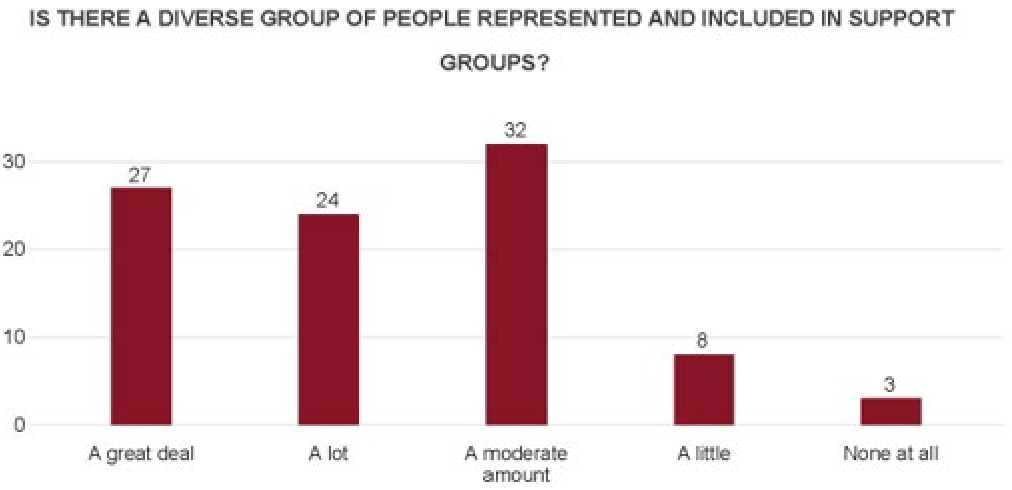




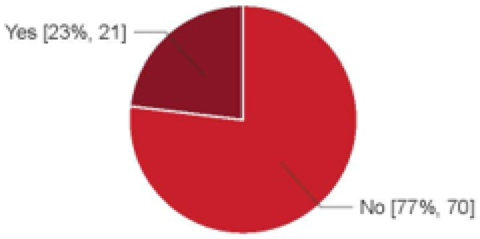

OTHER - TEXT

Other - Text
Again, big pharma is your main focus
only the fact that I didnt even know there were support groups. Also, it feels strange having a disease and not requiring treatment. I feel uncomfortable talking about my concerns with people who need treatment and are suffering - it makes me stay quiet.
Technological assumptions

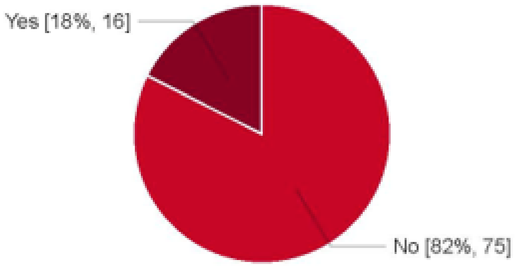
Current Diversity Standing and Attitude



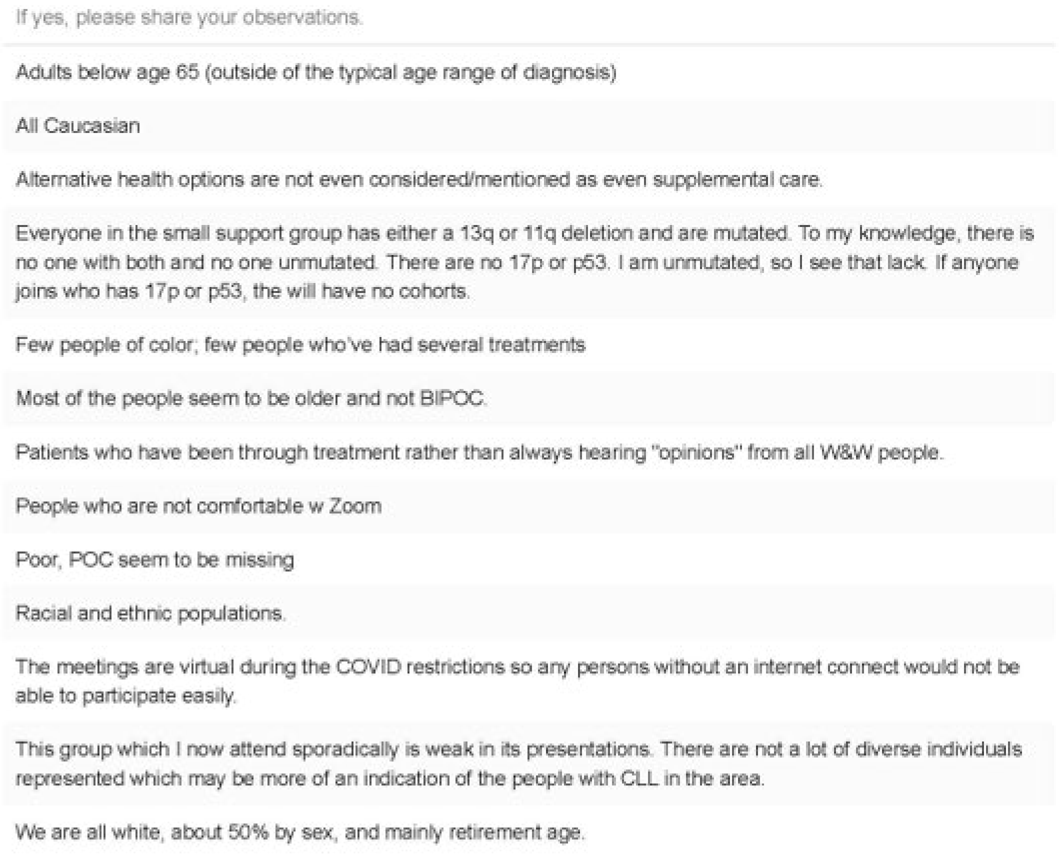
ARE THERE PEOPLE IN CLL SOCIETY SUPPORT GROUPS WHOSE OPINIONS AND CONCERNS ARE NOT RECOGNIZED?



ARE THERE PEOPLE NOT ADEQUATELY REPRESENTED IN CLL SOCIETY SUPPORT GROUPS?



SHARED OBSERVATIONS


If yes, please share your observations.

Adults below age 65 (outside of the typical age range of diagnosis)

All Caucasian

Alternative health options are not even considered/mentioned as even supplemental care.

Everyone in the small support group has either a 13q or 11q deletion and are mutated. To my knowledge, there is no one with both and no one unmutated. There are no 17p or p53. I am unmutated, so I see that lack. If anyone joins who has 17p or p53, the will have no cohorts.

Few people of color; few people who've had several treatments

Most of the people seem to be older and not BIPOC.

Patients who have been through treatment rather than always hearing "opinions" from all W&W people.

People who are not comfortable w Zoom

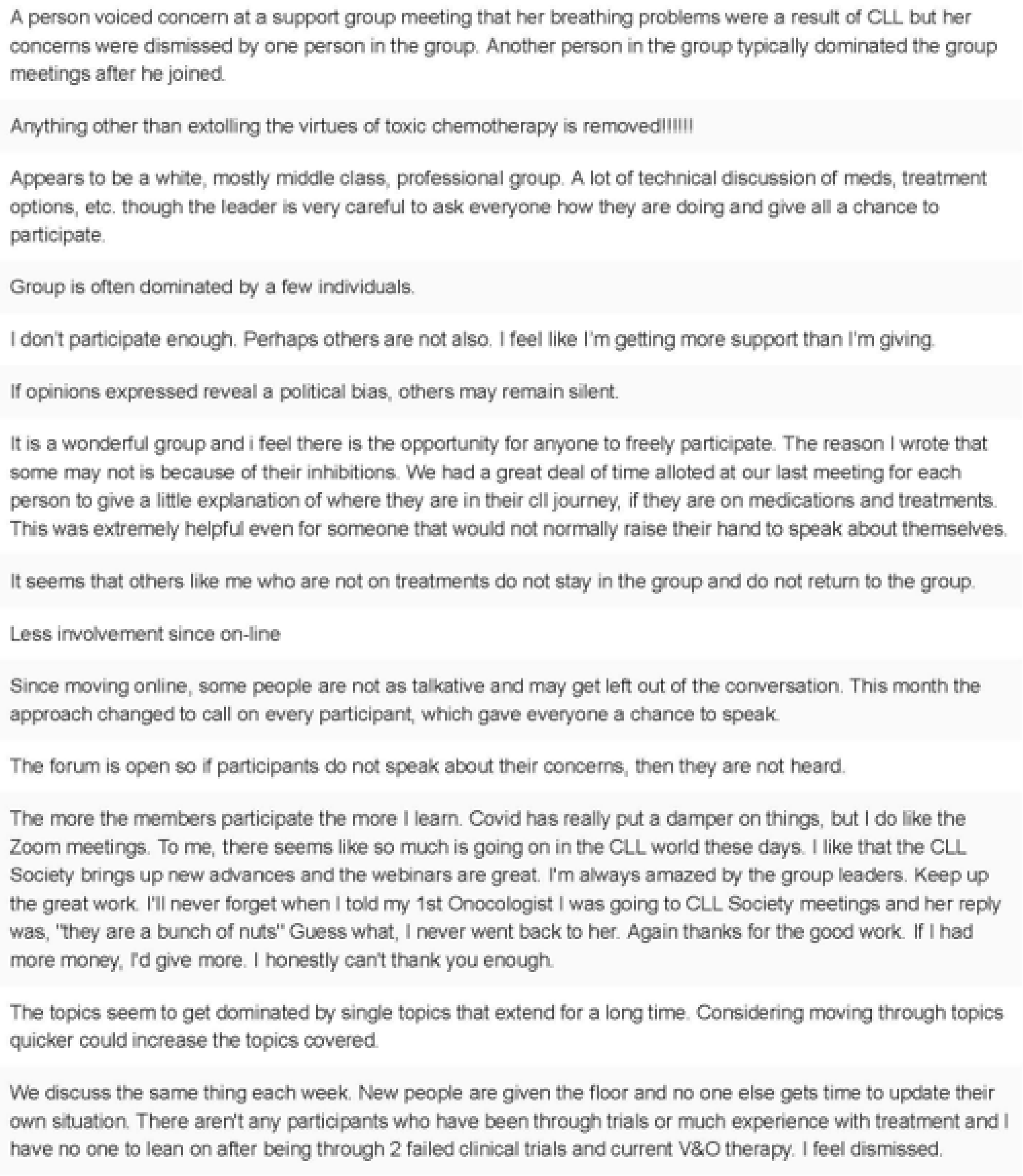
Poor, POC seem to be missing

Racial and ethnic populations.

The meetings are virtual during the COVID restrictions so any persons without an internet connect would not be able to participate easily.

This group which I now attend sporadically is weak in its presentations. There are not a lot of diverse individuals represented which may be more of an indication of the people with CLL in the area.

We are all white, about 50% by sex, and mainly retirement age.



A person voiced concern at a support group meeting that her breathing problems were a result of CLL but her concerns were dismissed by one person in the group. Another person in the group typically dominated the group meetings after he joined.

Anything other than extolling the virtues of toxic chemotherapy is removed!!!!!!

Appears to be a white, mostly middle class, professional group. A lot of technical discussion of meds, treatment options, etc. though the leader is very careful to ask everyone how they are doing and give all a chance to participate.

Group is often dominated by a few individuals.

I don't participate enough. Perhaps others are not also. I feel like I'm getting more support than I'm giving.

If opinions expressed reveal a political bias, others may remain silent.

It is a wonderful group and i feel there is the opportunity for anyone to freely participate. The reason I wrote that some may not is because of their inhibitions. We had a great deal of time alloted at our last meeting for each person to give a little explanation of where they are in their cll journey, if they are on medications and treatments. This was extremely helpful even for someone that would not normally raise their hand to speak about themselves.

It seems that others like me who are not on treatments do not stay in the group and do not return to the group.

Less involvement since on-line

Since moving online, some people are not as talkative and may get left out of the conversation. This month the approach changed to call on every participant, which gave everyone a chance to speak.

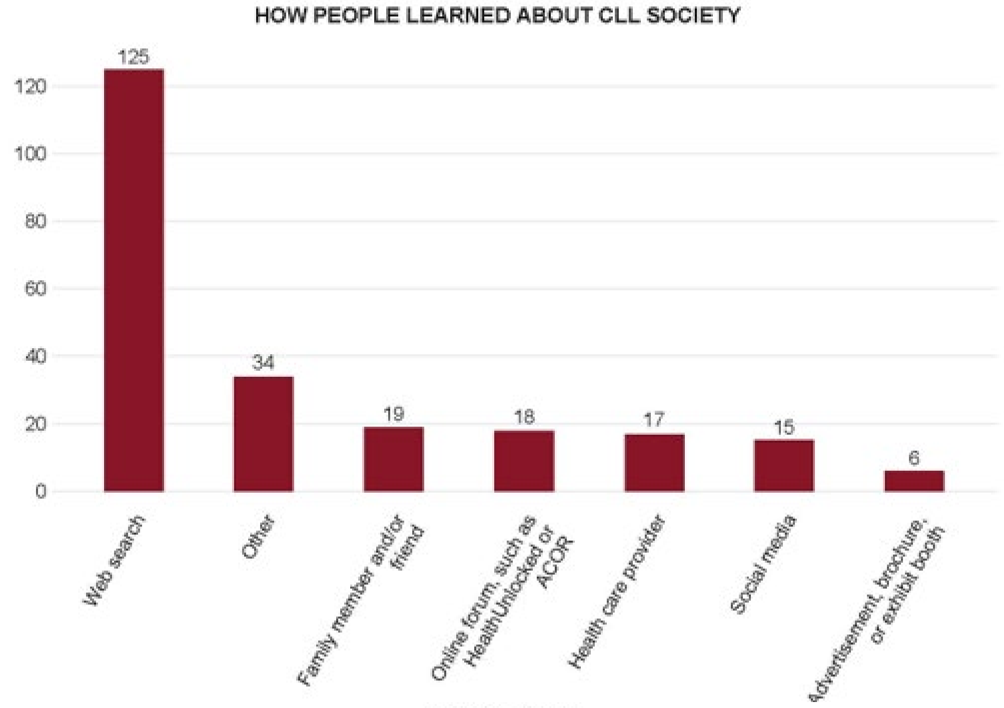
The forum is open so if participants do not speak about their concerns, then they are not heard.

The more the members participate the more I learn. Covid has really put a damper on things, but I do like the Zoom meetings. To me, there seems like so much is going on in the CLL world these days. I like that the CLL Society brings up new advances and the webinars are great. I'm always amazed by the group leaders. Keep up the great work. I'll never forget when I told my 1st Onocologist I was going to CLL Society meetings and her reply was, "they are a bunch of nuts" Guess what, I never went back to her. Again thanks for the good work. If I had more money, I'd give more. I honestly can't thank you enough.

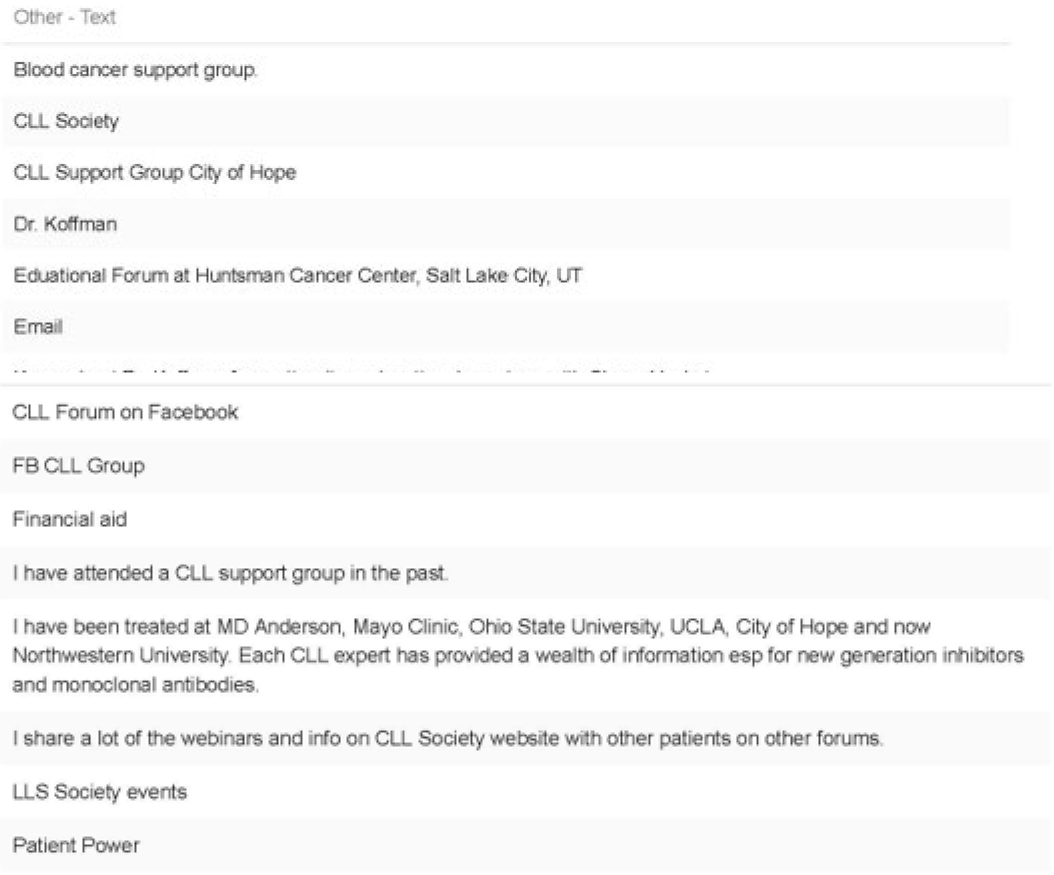
The topics seem to get dominated by single topics that extend for a long time. Considering moving through topics quicker could increase the topics covered.

We discuss the same thing each week. New people are given the floor and no one else gets time to update their own situation. There aren't any participants who have been through trials or much experience with treatment and I have no one to lean on after being through 2 failed clinical trials and current V&O therapy. I feel dismissed.

Current and Desired Forms of Engagement with CLL Society



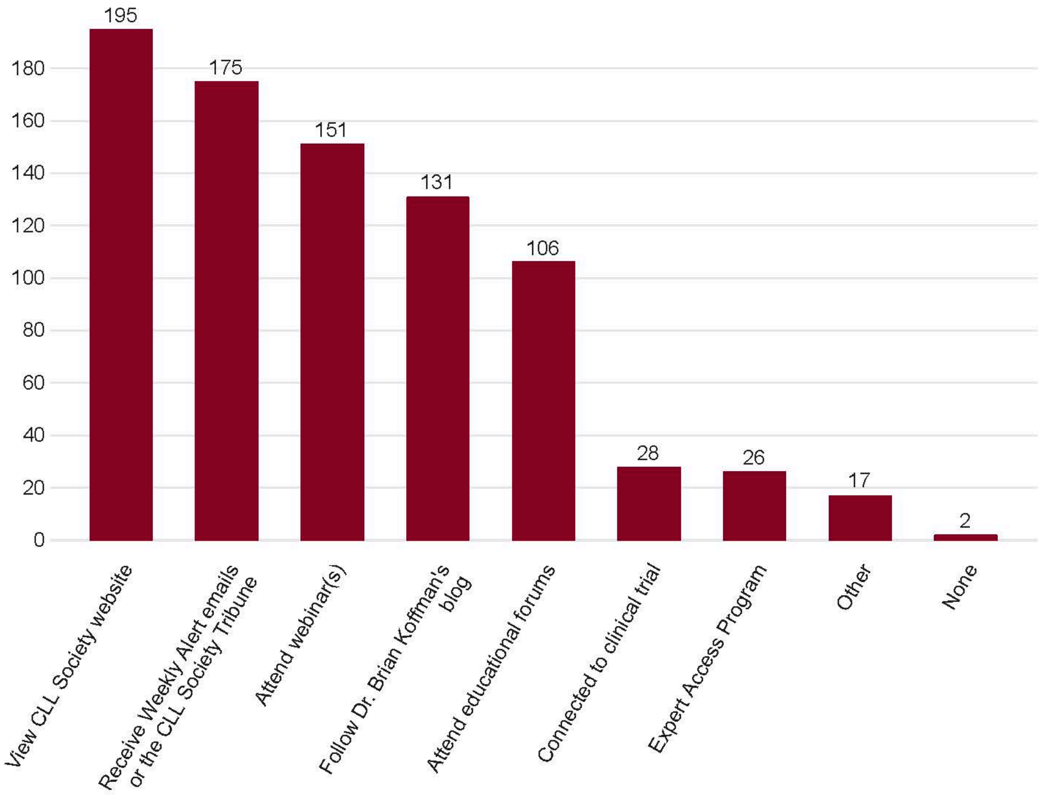
OTHER - TEXT



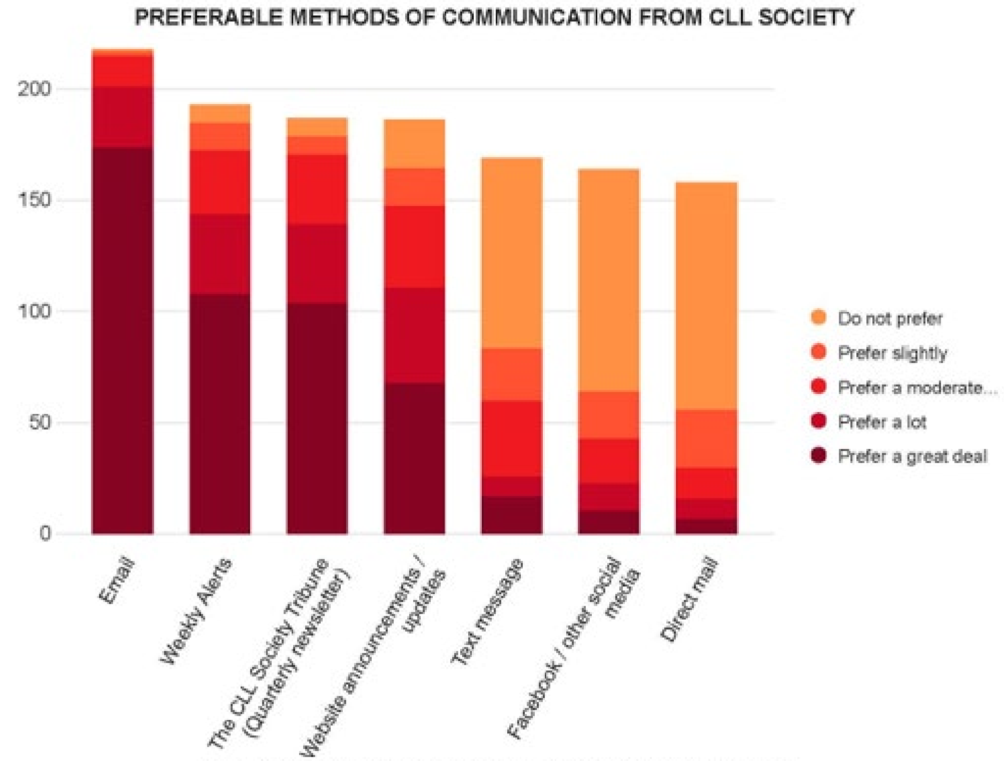
Other - Text
Blood cancer support group.
CLL Society
CLL Support Group City of Hope
Dr. Koffman
Eduational Forum at Huntsman Cancer Center, Salt Lake City, UT
Email
CLL Forum on Facebook
FB CLL Group
Financial aid
I have attended a CLL support group in the past.
I have been treated at MD Anderson, Mayo Clinic, Ohio State University, UCLA, City of Hope and now Northwestern University. Each CLL expert has provided a wealth of information esp for new generation inhibitors and monoclonal antibodies.
I share a lot of the webinars and info on CLL Society website with other patients on other forums.
LLS Society events
Patient Power

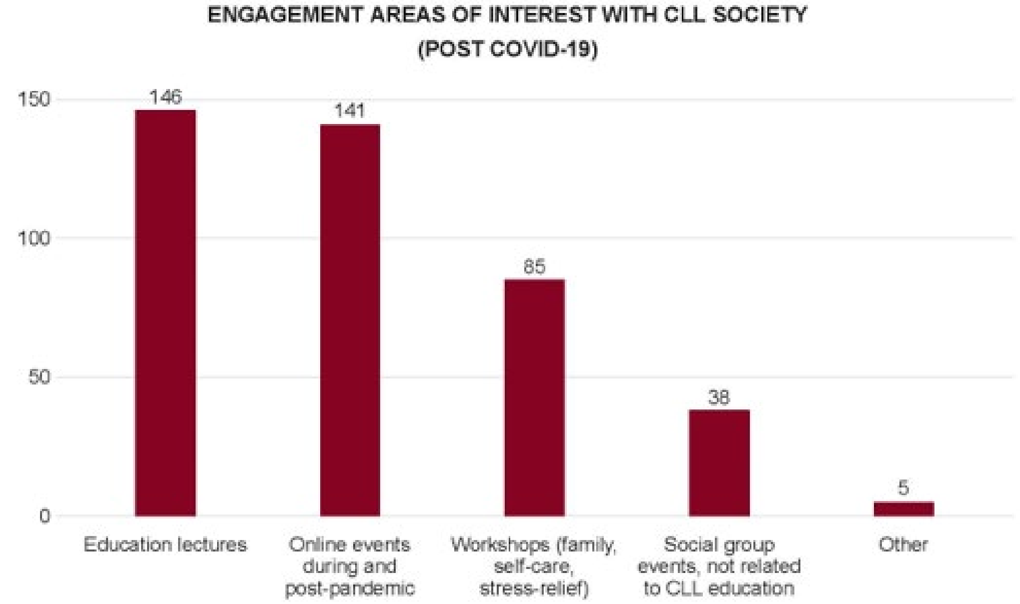
LLS
LLS
LLS Conference
LLS Patient Information Seminar Brochure?
LLSociety
a person
email

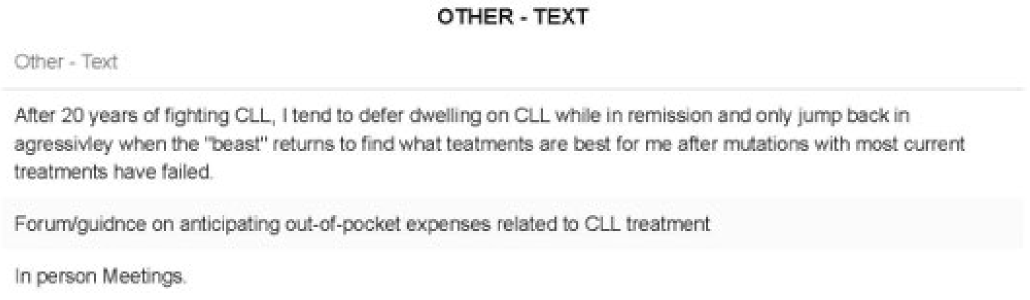
CURRENT FORMS OF ENGAGEMENT WITH CLL SOCIETY



Other - Text
CLL Forum on Facebook
FB CLL Group


PREFERABLE METHODS OF COMMUNICATION FROM CLL SOCIETY


ENGAGEMENT AREAS OF INTEREST WITH CLL SOCIETY (POST COVID-19)


OTHER - TEXT

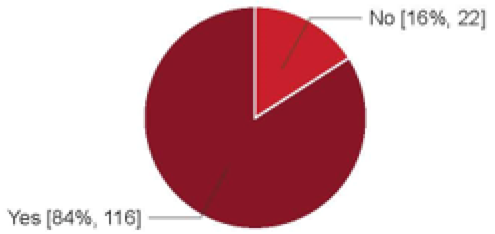
Other - Text

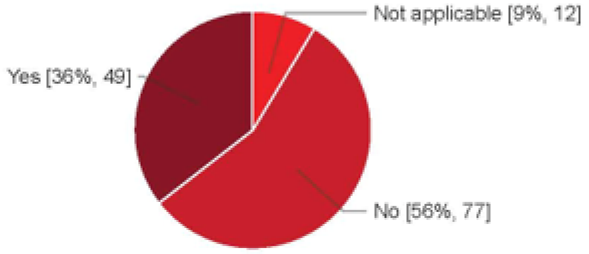
After 20 years of fighting CLL, I tend to defer dwelling on CLL while in remission and only jump back in agressivley when the "beast" returns to find what teatments are best for me after mutations with most current treatments have failed.

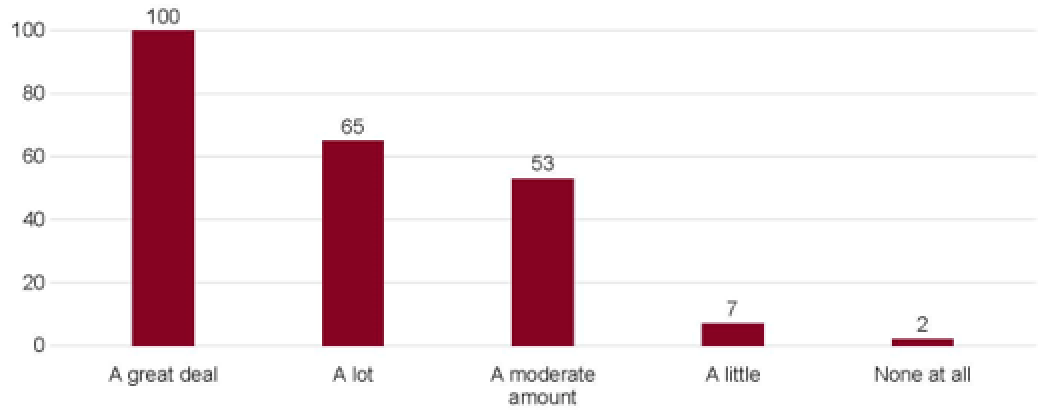
Forum/guidnce on anticipating out-of-pocket expenses related to CLL treatment

In person Meetings.

Need for Expansion of CLL Society Programs


DO YOU FEEL BEING A PART OF A COMMUNITY OF PEOPLE WITH CLL WOULD BE BENEFICIAL?


DO YOU FEEL YOUR LOVED ONES NEED A COMMUNITY AS WELL?


DO YOU FEEL KNOWLEDGEABLE ABOUT HOW TO ACCESS HEALTH CARE PROVIDERS AND A VARIETY OF RESOURCES FOR CLL?

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Clinical Trials

Overview

Facilitating clinical trials is not a main activity of the CLL Society, but CLL Society's placement in connecting clients to clinical trials is. CLL Society is in a prime position to push back on mistrust and inform their clientele. There are several reasons that minority clients do not participate in clinical trials and much of that boils down to mistrust. It is imperative that organizations work to take down the walls that may be blocking clientele from participating.

Our recommendations work to encompass all minority clients, but mostly focus on Black, Latinx, and Indigenous populations. The goal of these recommendations is a "meet them where they are" approach. Many of these recommendations focus on building better relationships and working with clientele in spaces that are already trusted. Much of this section will piggyback off the Community Outreach section.

Methods

The purpose of this section is to outline how the CLL Society can improve its messaging around clinical trials. As well as building trust of minority communities to increase their participation within clinical trials. To provide meaningful recommendations, we researched three areas. First, communities of color and clinical trials, then the history of mistrust in clinical trials, and finally clinical trials outside of the CLL Society. Currently, the CLL Society does not have broad participation from communities of color. Thus, we found that it was imperative to specifically address communities of color in our research and recommendations sections. Mistrust of clinical trials, especially within communities of color, is a significant barrier to participation in clinical trials. The CLL Society is aware that to increase participation in clinical trials, they must first reestablish trust between communities of color that was lost in part to historical abuse. We found that mistrust of clinical trials provided the most robust research and recommendations. Finally, the CLL Society can learn from other organizations, such as Merck and Athenex Oncology, which effectively market their clinical trials.

To prevent repetitiveness between our research and recommendations, we only included the most relevant components of our research in the subsequent sections. We first researched the three areas detailed above. When performing our research, we placed a special emphasis on how messaging and trust could be improved within clinical trials. Based on our research, we tailored specific recommendations to the CLL Society. These recommendations were again crafted with the intent of providing the CLL Society with the most effective strategies of improving their messaging and marketing around clinical trials, as well as establishing trust within clinical trials, specifically in communities of color. Further research on clinical trials can be found in the clinical trial section of the literature review.

Research and Findings

Communities of Color and Clinical Trials

Most clinical trials do not represent a diverse sample of the population[154]. There are many barriers that marginalized populations face that limit their entry into clinical trials. Some of these barriers include religion and health literacy, lack of trust because of historical abuse, lack of education on what the purpose of clinical trials are, and cultural and language differences.[155] There is a long way to go for researchers to increase diversity in clinical trials as race is not always reported in the data sets. A study conducted on disparity race reporting in cancer drug clinical trials from 2008 to 2018 found that participants' race was only reported in 145 out of 245 FDA clinical trials.[156] In the trials where race was reported, only 3 percent of participants were Black compared to 76 percent who were white.[157] More recently, in 2020 the FDA released new guidance on clinical trial participation with a provision on guidance for analyzing race and ethnicity data.[158]

Although there is evidence that communities of color are underrepresented in clinical trials due to being excluded from the initial phases, there is counter evidence that suggests that the problem has been occurring during phase III of clinical trials, where the goal is to test the efficacy of the product. A recent NIH report found that there is a good amount of minorities who participate in the first phase but are then left out of the third phase which may be a result of provider bias.[159] Subsequently this study suggests that changes need to be made in the way that scientists conduct their clinical trials rather than solely putting an emphasis on working to promote clinical trials among underrepresented communities.

To reiterate, there are multiple barriers that hinder BIPOC (Black, Indigenous, and People of Color) clients from participating in clinical trials. As our research states, barriers include language/cultural barriers, health illiteracy, and/or a lack of knowledge around the purpose of clinical trials.[160] For example, when looking to the Black community, there has been historical abuse in the medical field. This includes the well-known Tuskegee experiments, but also the continued medical mistreatment in the present time[161]. This shows there is a “laundry list” of reasons why BIPOC clients do not participate in clinical trials. Although, we can conclude that many of these reasons are rooted in mistrust and misunderstanding of clinical trials.

Recommendation #1: Build Better Relationships with BIPOC Clients

The capstone's first recommendation to the CLL Society is to build better relationships with BIPOC clients. Although this seems intuitive, it must be intentional. The first way to address mistrust is to "get to know your patients' perceptions and social determinants of health".[162] This means getting to know your patients, listening to their fears and mistrust, and checking for cultural differences in defining "health".[163] By offering BIPOC clients a safe and welcoming space to openly discuss their mistrust, the CLL Society can work to address that mistrust individually.

The CLL Society may also look to providing educational materials that are easy to understand and accessible to clientele. This could include highlighting stories from non-white clients who have experienced clinical trials. The CLL Society could also look to pre-made educational pamphlets that other organizations offer to conduct outreach to specific communities.

- **Redes En Acción[164]:** This organization provides a manual that gives guidance and resources to those offering clinical trials to Latinx populations. All their resources are available in English and Spanish. The available presentations use accessible and easily understand language to teach clients about clinical trials.[165] It also features stories from Latinx people who have participated in clinical trials.
- **UC Davis[166]:** The UC Davis Clinical and Translational Science Center created a short, general guide for Black people interested in clinical trials. Although it is a smaller resource, it works to use accessible language and combat mistrust that came specifically from the Tuskegee experiments.
- **Urban Indian Health Institute[167]:** This is a useful resource for those in the Indigenous community with questions about health issues like cancer, diabetes, and COVID-19. They provide a three-page guide on "Understanding Clinical Trials" and provide other guiding resources at the end of the document.

Recommendation #2: Education Campaigns

As our research stated above, people of color are often not represented within clinical trials due to barriers of entry such as health illiteracy, lack of education on what clinical trials accomplish, and lack of trust because of historical abuse. We would like to further emphasize the impact lack of education has on communities of color participation in clinical trials. In one study, a randomized controlled trial was conducted on 63 oncology patients, where the treatment group received an in-office education video on clinical trials and the control group did not receive in-office education. This study concluded that "increasing awareness and knowledge about clinical trials in underrepresented communities is an important step to providing opportunities for participation."[168] In addition, another study on clinical trial awareness among racial/ethnic minorities found that "lower awareness of clinical trials is at least a partial explanation for lower minority participation in trials."[169] This suggests that one potential way to combat low minority participation within clinical trials is through education campaigns.

We recommend that the CLL Society enact their own education campaign. It is not likely for a person to sign up for something that they do not know about. An education campaign would be beneficial in just getting the word out that these trials exist but also letting people know what these trials consist of. One way to get the message out about clinical trials could be through advertising whether this is via social media or commercials. Since the older population is largely affected by CLL, it would be beneficial to focus on social media applications that are popular among this age demographic. When thinking about marketing via commercials, it could also be beneficial to focus airing commercials on networks that are more prominently watched in the older community.

Another way to promote participation in clinical trials would be to directly educate underrepresented communities. This may be executed by providing educational resources to health care providers in rural communities as well as cultural competency trainings for doctors/physicians[170]. Subsequently, educating health care providers and other community leaders on the benefits of clinical trials, will have a trickle-down effect on the rest of the population.

Mistrust in Clinical Trials

Historically, minority populations have a deep-rooted mistrust of clinical trials. Much of this mistrust stems from the Tuskegee clinical trial for untreated syphilis in African American males[171]. These men agreed to be examined and treated, but there was no evidence that researchers had informed them of the study or its real purpose. Further, the men had been misled and had not been given all the facts required to provide informed consent.[172] Ultimately, the men were never given adequate treatment for their disease, and the advisory panel found nothing to show that subjects were given the choice of quitting the study, even when penicillin became widely used. As a result, many of these men succumbed to their disease and passed it to their family members.

Research shows that minority mistrust of clinical trials is still deep-rooted today. Black and Latinx participants in COVID-19 drug trials were about 19% according to Pfizer.[173] Further, research also shows that people of color typically receive less and worse care than white Americans. A recent study found that care for black patients is significantly better when they are being treated by a black doctor. Those who saw black doctors received 34% more preventative care than when they saw white physicians.[174] Due to the unethical use of minority populations in earlier clinical trials, many now have strict regulations as well as ethical checks and balances. Currently, clinical trials have diversity requirements so researchers can understand how different bodies react to different drugs and treatments[175].

Our research shows that individuals in the medical field are working to combat mistrust, but we want to ensure we are providing the CLL Society with recommendations that match the organization. Therefore, we have one robust recommendation for the CLL Society to tackle the issue of combating mistrust within clinical trials.

Recommendation #3: Utilizing Community Spaces and Leaders

Although you have likely seen a similar recommendation from our Community Outreach section, we thought it was important to create a recommendation that more broadly covers BIPOC clients. Most programs have found that the most successful engagement of BIPOC communities is by tapping into community spaces and trusted leaders.[176] When looking at recruitment and retention, “projects taking a community-engaged approach were more successful in retention.”[177] Organizations, physicians, and researchers can work with these leaders to spread the message and work through mistrust.

Utilizing these recommended spaces has many positives, but it is important to note some of the challenges in doing this type of outreach. Typically, it is labor intensive and requires dedication of time and resources[178]. Because the CLL Society will need people to visit these places and work alongside these communities, we believe this is a great opportunity to engage community volunteers. We recommend that the CLL Society recruits community volunteers to lead their efforts in combating mistrust. Volunteers can be trained and deployed to their communities to start conversations around clinical trials and help recruitment efforts. We offer examples of community spaces below:

- For Black clientele, the most promising community spaces appear to be churches and barber shops.[179] The Black population is one of the largest ethnic groups that attends church in the nation. Although most experts state that these cannot be the only spaces where targeted messaging happens because they typically miss specific pockets of the Black community.[180] These pockets could include LGBTQ+ individuals who have experienced homophobia, those who do not attend church, and those with minor physical differences, like bald men.[181]
- The Latinx population is one of the most geographically and culturally different populations and that is reflective in their needs.[182] Since many Latinx values lie in “familia,” many rely more on a trusted network of individuals in their community.[183] In one study, researchers found major success in using health care workers, librarians, and activists to establish trust and maintain relationships.[184] These relationships were key to their successful recruitment efforts.

- Indigenous populations are complex communities to access.[185] Most experts suggest spending time “meeting with tribal leadership in their home communities rather than assuming” they would want to drive to you.[186] It is imperative for those wanting to recruit Indigenous populations to be aware of tribal leadership changes and to be mindful of specific tribal nation policies.[187]

We recognize that the CLL Society’s focus is not on recruitment for clinical trials, but we believe that the CLL Society will be more successful in reaching their clientele in spaces where they are comfortable. It is important to have both individual conversations, but also community-wide conversations about mistrust. We recommend this holistic approach as it is flexible and can be tailored to where the organization is at in any given time.

Clinical Trials Outside of the CLL Society

For the CLL Society to improve marketing and messaging around their clinical trials, research had to be conducted on how clinical trials were marketed outside of the CLL Society. Research suggested that organizations such as Athenex Oncology market their clinical trials as a pipeline, where their robust investigational pipeline is “focused on both improving outcomes and improving cancer treatment experience for patients around the world.[188] Merck markets their clinical trials through a user friendly search browser embedded within their website that allows patients to filter on their condition, location, age, and sex. When a patient clicks on a specific cancer/condition category, he/she is taken to a page where a short explanation is provided about the various types of cancers within that category. Patients then scroll to the bottom of the page where they can explore various clinical trials associated with their condition. The trial name, condition(s), and phase are provided. When a patient clicks on the trial name, a short explanation is provided about the specific trial. Patients can then see if they are eligible for that trial.[189] The key point for both organizations is that all the information around clinical trials is provided in a user and patient friendly way. There is little to no medical jargon that patients may not understand, and simple informative graphics are provided as another form of information sharing.

It is important to note that both Athenex Oncology and Merck have diverse clientele. Both organizations support a wide range of cancer clinical trials, which ultimately influences the ways in which they communicate their clinical trials to potential clients. Allowing users and patients to apply multiple filters within their clinical trial search enables them to find the best clinical trial for their needs in a relatively quick, efficient way. However, it is important to note that research suggests that no organizations were found to be successful at recruiting diverse populations.[190] There are many barriers of entry, including low socioeconomic status. More literature surrounding the barriers to entry for clinical trials can be found in the clinical trials section of the literature review.

It may be hard for some people to comprehend what exactly takes place during the clinical trials of a new drug. Although a physician may explain the treatment that one will undergo during a trial, no one anticipates the other effects the trial will have on one's life. The CLL Society's website contains many beneficial resources for people who would like to learn more about Chronic Lymphocytic Leukemia; but there are few resources for people who want to know what life is like during the trial. Because of this, we have provided two recommendations for the CLL Society to update their website to meet all their clients and participants' needs.

Recommendation #4: Update Website to Include Most Relevant Information

First, we recommend that the CLL Society use targeted messaging that focuses on how clinical trials impact minority groups like people of color and women. These communities are underrepresented within clinical trials and lack trust in medical professionals.[191] For these reasons, the CLL Society needs to establish strong relationships with these minority groups and include messaging and information specifically about these communities on their website.

Additionally, we recommend that the CLL Society update their "The Basics" page to include more recent articles about clinical trials for cancer treatments. Another helpful addition to this page would be including graphics that display the different stages of treatments a patient receives. These graphics can aid participants in understanding what they may experience throughout the clinical trial. While participants may be unable to control what affects their bodies experience during the clinical trial, they need to know that there are several aspects they can control to improve their condition during this time. Although the CLL Society's website includes great resources for participants, we suggest including resources for healthy diets, workout routines, and ways to relieve stress under their "Living Well with CLL" page. We recommend the CLL Society structuring this page in a similar way to Athenex. Here the CLL Society can view sample nutrition, stress, and physical wellness guides that may prove beneficial for their clientele.

Recommendation #5: Make Website More Accessible

We recommend that the CLL Society creates a more accessible website to their users and patients. First, we recognize that the CLL Society website is already available in four languages. We think that is a great start but could continue to be built upon. With this, we recommend that the CLL Society provide further translations of the website to be inclusive of the increasingly diverse population in the United States. The website is missing translation in Mandarin or Cantonese Chinese which is one of the most common languages spoken in the country.[192] This would continue to break down those barriers of misunderstanding and give more people the chance to have access to the same resources as their English-speaking peers. Additionally, we recommend that the CLL Society simplifies as much language on their website to laymen's terms for those individuals who are not familiar with medical terminology.[193] The CLL Society could also provide an online glossary with typical medical terms. These updates and tools will help the CLL Society's clients better understand the content.

Finally, we recommend that the CLL Society incorporates more video and audio messages into their website. First, audio messages will make the website's content more accessible for clients who are legally blind or vision impaired, and video messages could include subtitles for those clients with hearing impairments.[194] Furthermore, we recommend the CLL Society expand their patient video compilation, where previous and current patients detail their stories about their experiences within the clinical trial. This expansion in video content will help current or prospective participants understand what the patient experience is. It will also aid them in their decision about whether they want to participate in a clinical trial.

Conclusion

In summary, mistrust in clinical trials is a huge obstacle that the CLL Society will not be able to fight on their own. The CLL Society will have to work alongside other organizations, physicians, community health workers, etc. to tackle this giant task. Mistrust must be confronted from all sides of the healthcare system.

In the meantime, we believe these recommendations can help CLL Society work within their organization and with current clientele to combat mistrust. By building meaningful connections with BIPOC clients, working within trusted spaces and alongside community leaders, and making accessibility improvements to the website, the CLL Society can begin chipping away at their clients misunderstanding and mistrust in clinical trials.

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Board Development

Overview

Our objective for the board development section of the report was to develop a plan to aid CLL Society in expanding diversity, equity, and inclusion on their Board of Directors. To meet this objective, we focused our research on four broad areas. First, we conducted an analysis of the current board composition and bylaws. Second, we considered best practices for recruiting new diverse individuals. Third, we outlined standard procedures for creating a DEI committee on the board. Finally, we compiled resources for conducting DEI training and professional development for board members and staff.

CLL Society's Board of Directors Profile

Methods

To begin our analysis of Diversity, Equity, and Inclusion (DEI) within CLL Society's Board of Directors, and to help guide our recommendations for further incorporating DEI into the Board's structure, we first needed to determine the demographics of current Board members and analyze the organization's current Bylaws. Doing so allowed us to create a profile reflective of CLL Society's present position.

To determine the demographics and DEI-related attitudes of current board members, we designed a 14-question survey using Google Forms. The survey contained 11 multiple-choice questions, two "check-all-that-apply" questions, and one optional short-answer question. We distributed the survey electronically to each of CLL Society's seven board members via our project liaisons. The survey was distributed on February 19, 2021 and remained open for responses until March 5, 2021. We informed participants that the purpose of the survey is to gather demographic and diversity information from CLL Society Board members to help with the development of our DEI plan and that all responses would remain anonymous. We asked participants to identify their gender, age, race or ethnicity, highest level of education, the language(s) they can speak fluently, whether they have a disability, and what type of community they live in (e.g., urban, suburban, rural). In addition, we posed several statements and asked participants to rank how strongly they either agreed or disagreed with each statement to gauge how board members felt about the current DEI climate within the organization and about incorporating additional DEI initiatives into the Board's structure. The statements we posed were as follows:

- “There is cultural diversity among the board members of CLL Society.”
- “CLL Society has done a good job promoting diversity and inclusion within the organization.”
- “CLL Society has done a good job providing training programs that promote diversity and inclusion.”
- “I would like to see diversity, equity, and inclusion training programs made available for CLL Society employees and board members.”
- “I would be open to attending diversity, equity, and inclusion-related trainings for CLL Society employees and board members.”
- “I would be open to incorporating a Diversity, Equity, and Inclusion committee into CLL Society's board.”

Participants were able to indicate their level of agreement by selecting either “Strongly disagree”, “Disagree”, “Neutral”, “Agree”, or “Strongly agree” for each statement. Finally, we asked board members to provide a written response to the question, “In what ways do you believe diversity could be improved on the Board?”. Once we collected survey responses from each of the board members, we used Google Forms to develop visual summaries of the data collected for each question (See Appendix A for full summary of survey results). Our analysis is based on the data from the six responses we received during the two-week period. Limitations included a small sample size of self-selecting participants and the two-week time constraint.

Finally, we requested access to CLL Society’s current Bylaws via our project liaisons. We assessed the Bylaws for relevant information on the organization’s board structure, the specific powers of the Board, committee creation and committee types within the Board, and financial obligations and restrictions for board members.

Both assessments revealed useful information about the current board structure and demographics as well as the perspectives held by board members regarding DEI initiatives within the organization. This information allowed us to establish a profile of CLL Society’s current position and helped inform our recommendations for incorporating DEI within the board structure.

Findings

Key Findings from CLL Society Board of Directors Diversity and Inclusion Survey Results

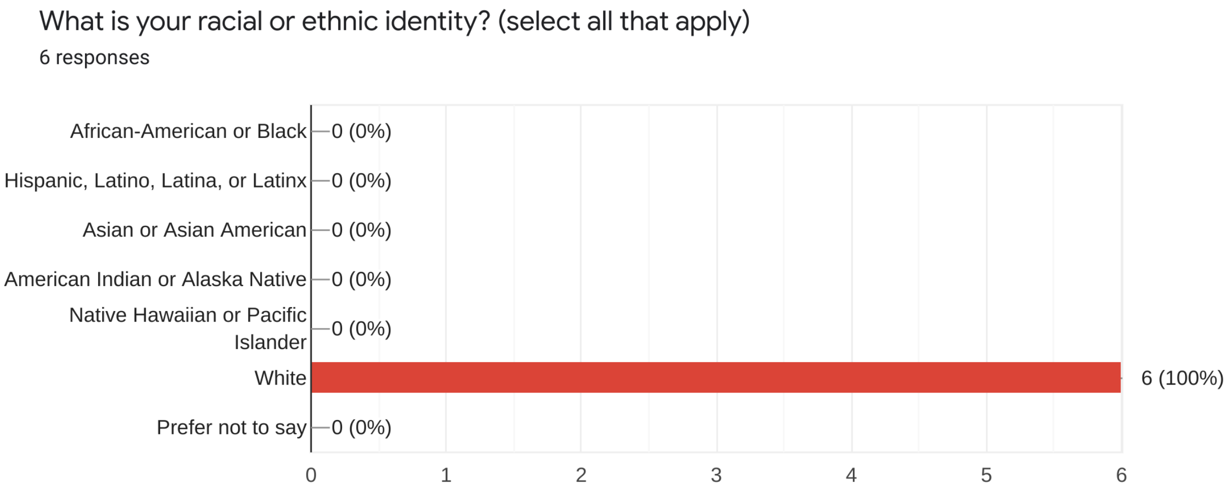
- All members of the Board identify as white or Caucasian.
- Five out of six board members identify as male. One member identifies as female.

- Most board members identified as being over the age of 50, with a third identifying as being between the ages of 60 and 69.
- Of the board members that responded, five out of six have completed a master’s degree or higher, with half having completed a doctorate degree.
- There is an even divide between the geographic locations of board members, with ⅓ living in urban areas, ⅓ living in suburban areas, and ⅓ living in rural areas.
- When presented with the statement, “There is cultural diversity among the board members of CLL Society,” ⅔ of participants responded either “disagree” or “strongly disagree”.
- When presented with the statement, “CLL Society has done a good job promoting diversity and inclusion within the organization,” half of all participants responded either “agree” or “strongly agree”.
- When presented with the statement, “I would be open to attending diversity, equity, and inclusion-related trainings for CLL Society employees and board members,” most participants responded either “agree” or “strongly agree”.
- When presented with the statement, “I would be open to incorporating a Diversity, Equity, and Inclusion committee into CLL Society's board,” the majority of participants responded either “agree” or “strongly agree”.

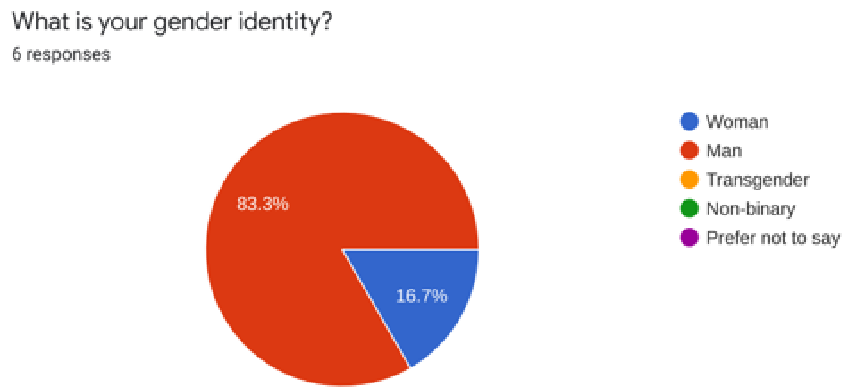
CLL Society Board of Directors Diversity and Inclusion Survey Results

This section provides visual summaries of the key findings from our survey results. To view the full results of the survey, please see section Appendix A.

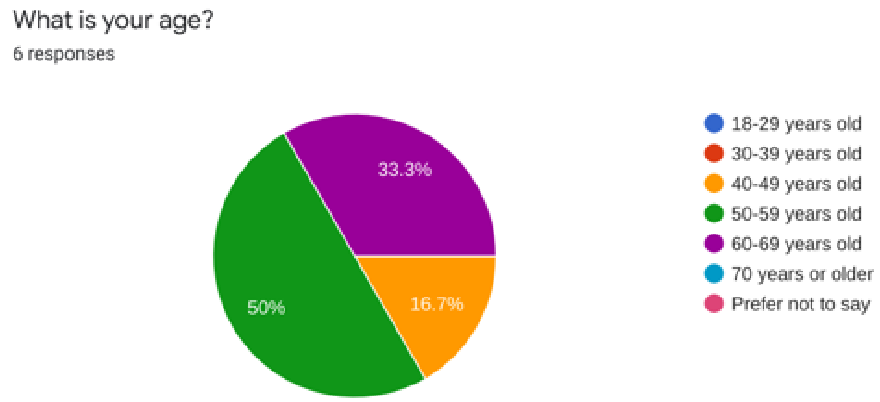
Racial or Ethnic Identities of Board Members



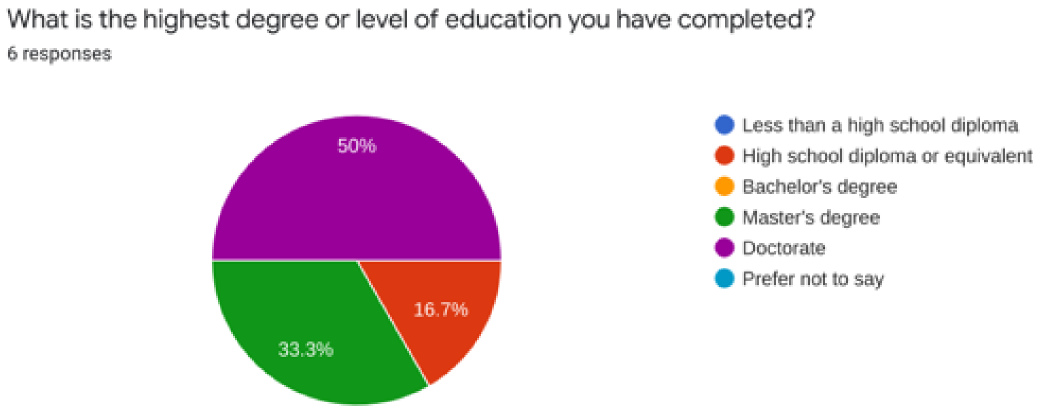
Gender Identities of Board Members



Age Groups of Board Members



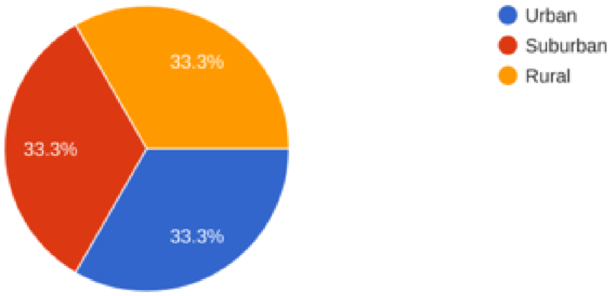
Education Level of Board Members



Geographic Locations of Board Members

Which of the following best describes the area you live in?

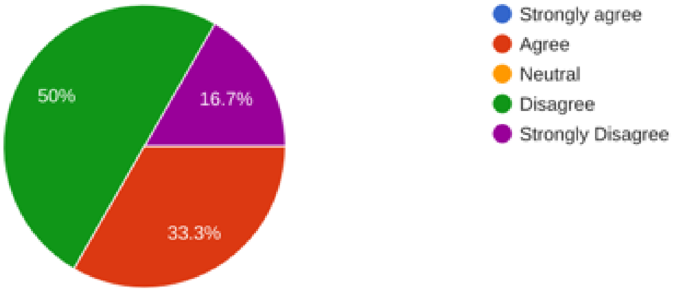
6 responses



Board member level of agreement to DEI-related statements

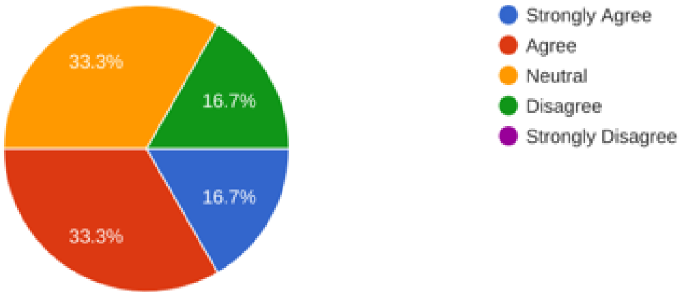
There is cultural diversity among the board members of CLL Society.

6 responses



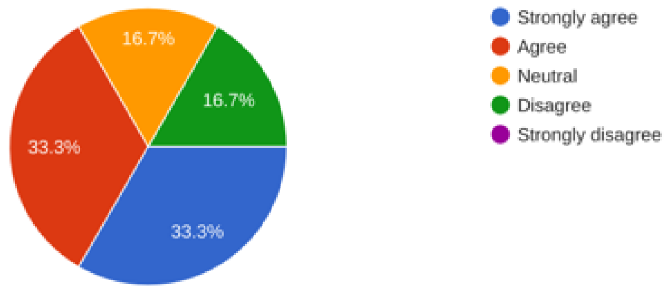
CLL Society has done a good job promoting diversity and inclusion within the organization.

6 responses



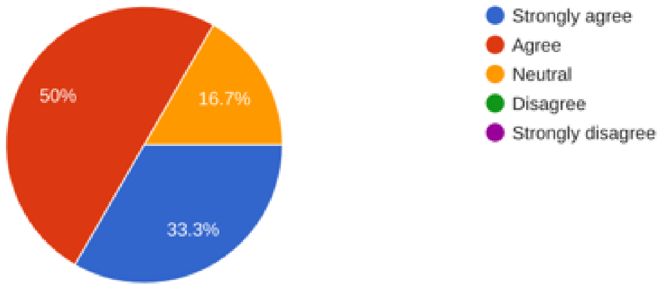
I would be open to attending diversity, equity, and inclusion-related trainings for CLL Society employees and board members.

6 responses



I would be open to incorporating a Diversity, Equity, and Inclusion committee into CLL Society's board.

6 responses



Key findings from CLL Society Bylaws Assessment

- There is a maximum of 11 members on the Board of Directors, and this number can be increased with a majority vote by the Board.
- The Board allows for the establishment of Standing Committees, Ad hoc Committees, and advisory committees at any time.
- Persons may be elected as honorary or advisory members by majority vote of the Board.

Conclusions

The results of the survey indicate that CLL Society's Board of Directors is primarily composed of white males over the age of 50. While this corresponds to the demographic group most likely to develop CLL, we know that CLL can impact any group, regardless of race, age, or gender. To provide an inclusive environment for patients, and to effectively incorporate DEI initiatives into CLL Society, it is important to construct a diverse Board of Directors. Diversifying the Board through the recruitment of new members will introduce new ideas, perspectives, and expertise that will help the organization connect with patients from all groups and geographic locations.

Finally, incorporating DEI into the structure of the Board should go beyond simply diversifying board members. The creation of a DEI-focused committee within the Board, as well as DEI trainings for board members and staff, can help integrate sustainable DEI initiatives into the Board's structure that will allow CLL Society to create an inclusive and supportive environment for all patients now and into the future. Our recommendations for implementing these initiatives are outlined in the following sections.

Best Practices for Taking a DEI Approach to Board Member Recruitment

Methods

In our exploration of DEI oriented board recruitment strategies for CLL Society, our research strategy consisted of gathering qualitative data from websites, articles, and reports detailing the board recruitment insights of other professional organizations. Throughout the research process, we discovered a plethora of information and resources for building a stronger, more diverse board. This section reviews major themes present across the available literature to provide a solid foundation for CLL Society's future board recruitment efforts.

The focus of our research was two fold. First, we wanted to gain an understanding of how diversity on the board can be advantageous to a nonprofit organization. Second, we wanted to compile a list of best practices when going about increasing diverse representation and inclusion on a board of directors.

Based on the findings of our research, we provide multiple recommendations for increasing board diversity and recruiting new members to the CLL Society Board of Directors through a DEI lens.

Findings

Through our research, we settled on three primary factors to consider when an organization is seeking to diversify its board of directors:

- The importance and value in having a diverse board of directors
- Preparing internally to begin DEI-informed board recruitment
- Recruiting diverse individuals in an intentional and respectful manner

First, we considered the value that increased board diversity brings to the organization. In an article written by the National Council of Nonprofits, a diverse board is characterized as being able to produce a wider array of ideas and have greater decision-making capacity as there are more individuals from different personal and professional backgrounds to share expertise. Consequently, the greater amount of diverse perspectives makes the organization more resilient to changes that can occur in the future and capable of handling risks. Additionally, more opportunities are inevitably brought to the organization through the various backgrounds and networks of diverse individuals, providing avenues of growth for the organization to pursue that would otherwise go unnoticed or be inaccessible.[195]

Another consideration for the value of enhancing board diversity is the difference a diverse board can make for the community an organization is serving and supported by. It is becoming a widely recognized concept that when the staff and volunteers of a nonprofit reflect the community it serves, the organization can serve the community in a more impactful manner. Each board member has a different set of community resources available to them, and likewise available to the organization to leverage working towards its mission. Moreover, bringing diverse individuals onto the board therefore increases the organization's reach to community resources.[196] In a study done by BoardSource, it was identified that diverse boards are becoming increasingly important to donors and grant makers. Broadly, funders value and seek out nonprofits who serve a diverse population and are nondiscriminatory in the provision of their services. Lacking diversity in board members can be an indicator to funders that diversity is not of importance to the organization and can result in the loss of potential donations.[197]

In addition to recognizing the benefits of diversifying the board, it is also important to acknowledge the risks of not diversifying. One major risk outlined by the National Council of Nonprofits is that the board will become stagnant. When everyone on the board comes from similar backgrounds and has overlapping networks, it is more challenging to develop innovative solutions to problems and new opportunities. Furthermore, a homogeneous board will not only have a harder time identifying diverse board prospects, but they will also struggle to retain those they are able to recruit if diversity is not an ongoing priority.[198] Correspondingly, Pillar Nonprofit Network has a toolkit for nonprofits looking to promote board diversity that outlines costs associated with not doing so. Beyond what has already been discussed, this organization finds a lack of diversity leads to lower morale in staff and board members, the cultivation of an environment that is unwelcoming to diverse individuals, and inaccurate conceptions of issues the organization aims to address leading to inaccurate communication to the public.[199]

Before an organization can start recruiting for a diverse board, it is important to prepare for the process and have a concrete vision of the end diversity goal. Perhaps the most advantageous place to start is with an internal analysis of the current culture of the board, and organization, to determine how welcoming it is for new and diverse members. Organizations should ensure they are set up for new board members to have a positive experience that makes them even more passionate about the mission and cultivates a desire in them to stay long term. According to a BoardSource blog posting, some ideas to create a welcoming environment include:

- Place new members on a committee right away to increase their participation in board activities.
- Establish a mentoring system where new members are paired with long-term members to learn and present ideas in a more informal environment.
- Analyze if social events are welcoming to all members and if there is willingness to alter them as needed.
- Ensure there is buy-in from all board members to create a space where new board members with diverse experiences can share ideas, be valued, and incorporate those ideas into organizational plans.
- Devote time to evaluating the impact that increased inclusion of diverse perspectives has had on the board and organization.[200, 201]

Once a solid analysis of organizational culture has been completed, establishing clear definitions for what a diverse board looks like for the specific organization is another highly beneficial preparatory action. This should be a process where the whole board participates, strengthening buy-in on board diversity from every current board member. An ideal starting point for determining what the organization is striving for in diversifying the board is to engage in broad discussions surrounding DEI topics. Doing so allows board members to gain a deeper understanding of reasons for working towards diversity and to become more comfortable with the concept. In combination with discussions around the meaning of diversity to the organization, board members should work together to seek to identify and understand their own implicit bias. While this is often not a comfortable activity to engage in, it is crucial to do as everyone is affected by implicit bias and it can hinder DEI efforts. Together board members can develop statements on commitments to diversity and building a workplace that is inclusive to all individuals regardless of identity. The finalized statements should be displayed in a manner that is visible to everyone who engages with the organization so the community, including prospective board members, see diversity and inclusion as values for the organization.[202, 203] Formulating the organization's commitment to strengthening DEI efforts into a written document can help keep the board on track as it works towards the defined goals. It can also help current board members gain an understanding of how adding diversity to the board will benefit the organization and its capacity to achieve the mission.[204]

Another useful exercise for board members to engage in when planning to become more diverse is to construct what BoardSource calls a "board matrix." This matrix should be a comprehensive chart of all members and their skills, profession, leadership style, network, backgrounds, and any other information the organization feels is important to include. The intention for the matrix is to identify gaps between the current skill set of the board and desired skills that would benefit the organization. However, this tool should not be used in a “checklist” fashion where potential members are recruited solely to fill a certain gap. Rather, a holistic approach should be taken to every candidate recruited for the board that acknowledges their professional expertise, background, networks, and more, beyond their racial identity.[205, 206]

Other important considerations in building a diverse board are the size of the board and term limits. According to BoardSource’s 2017 report *Leading with Intent*, there is no correct answer for a nonprofit on either of these characteristics. What the report found is that the average board size in the United States sits around 15 people and the average term limits are two consecutive three year terms. Furthermore, the report noted that only 72% of all nonprofits have term limits for their board members.[207] When determining the number of new members the organization wants to bring on, and the total number of members allowed on the board, the number should not constrict the broader diversity goal. The focus should remain on seeking out individuals who would add value, new perspectives, and resources to the board. Having a set number of new members to add may or may not end up helping to reach that goal.[208] Regarding term limits, they can create smooth transitions for ushering in new talent and ideas that move the organization forward over time. In both cases, the agreed upon factors should be ones that fit the unique needs of the organization.[209]

To aid organizations in starting the diversification process, BoardSource has developed a list of five questions for organizations to ask themselves. Having a solid answer to these questions will set organizations on the path to acting on increasing diversity in a meaningful way. The questions are as follows:

1. “Is our organization’s reputation being negatively (or positively) impacted by our board’s current composition vis-à-vis diversity?”
2. “If someone were to make assumptions about our organizational values based on our board composition, what would they be likely to think?”
3. “How well are we cultivating a deeper understanding of the community or communities that we serve and bringing their perspectives, needs, feedback, and priorities into our strategic boardroom discussions?”
4. “Are we ever at risk of making decisions without fully understanding how these decisions may affect those we serve?”
5. “If we were to make a deeper commitment to diversity, inclusion, and equity, what would that mean for our mission, our work, and the people we serve?”[210]

When an organization has finally prepared to recruit with more of a DEI lens, it must be intentional and reflective about its recruitment strategies. Even when organizations have the best of intentions, they can still make mistakes. A blog post from BoardSource provides great insight into how majority white organizations can go about recruiting diverse individuals in intentional and respectful ways. The key takeaway from this article is that organizations must be able to justify the value a specific individual can bring to the organization, and it must go beyond the organization's aim to diversify. It is not uncommon for a prospective individual to expect an explanation for why they are being recruited. Correspondingly, it is of crucial importance for organizations to know the background and skills the individual possesses and be able to convey how they would benefit the organization. The incorporation of diversity on a board of directors is about more than just race, and must involve seeking out various skills, expertise, and personal backgrounds to be successful. This is not to say race should not be considered an important factor, but that making it the only factor misses the ultimate goals of DEI work. Promoting race, or meeting diversity goals, as the main reason an individual is being recruited can feel especially tokenizing and prevent the individual from accepting the offer to join the board.[211] One method to minimize tokenism implications is to strive for 30% of the board to be made of diverse individuals. The idea here is to achieve a critical mass of diverse perspectives to ensure their opinions are valued and they do not feel isolated or treated as the sole voice for their demographic group.[212]

It can be hard to know where to look for the right candidates to add to the organization's board of directors. While leveraging current board member networks for prospects is often tempting, doing so will only bolster the present diversity issue. Organizations serious about diversifying must expand beyond existing networks of the organization. This process will likely be time consuming but being patient and intentional will reveal the best candidates for the board.[213] Listed below are a couple resources that can be useful for finding new prospective board members:

- Request suggestions of who to place on the board from the constituents the organization serves and set up a meeting with those individuals. People being served by the organization know best what they need from the organization.[214]
- Put technology to work. There are websites for nonprofits to post open board positions similarly to how the organization would post a job opening. LinkedIn also has a program, "LinkedIn Board Member Connect" that connects nonprofits to potential board members.[215, 216]
- Consider engaging with ethnic professional organizations and ethnic civic associations at the local and national level.[217]
- Look to other community entities and organizations such colleges and MBA/MPA programs, leadership programs, professional associations and fraternal organizations, boards of similar nonprofits, and leaders in the community or relevant areas of work to the organization, among others.[218]

It is not enough to simply place diverse individuals on the board, their opinions must be heard and valued. They must be included in board activities, not just present at meetings. Below are cautionary factors outlined by the Avarna Group that should be considered when beginning the process of diversifying a board of directors.

- **Being the sole individual of color can feel tokenizing**
  Promoting race as a key reason for recruiting an individual, regardless of the other beneficial skills the individual possesses that benefit the organization, can make it appear to the individual that the organization only cares about appearances.
- **Being the sole individual of color can be isolating**
  It can be lonely and intimidating to be the only one in the room presenting different ideas and experiences.
- **A single person is not able to represent the experience of an entire population**
  There is not one experience held by every single person of a race and expecting one person to speak for an entire race is incredibly problematic and works against the goals of DEI.
- **Being a person of color does not qualify someone to do DEI work**
  Incorporating principles of DEI into the workplace and other spaces is a trained profession and not just any person of color can do it.
- **There is a difference between representation and culture change**
  Having people of diverse backgrounds on the board is only one piece to striving for DEI that alone does not achieve change in the organization.[219]

Conclusions

Establishing a diverse board of directors for a nonprofit organization takes time and dedication. But the value received from having multiple perspectives and expertise on the board is well worth the effort. A diverse board is better situated to develop more innovative ideas, have greater decision-making ability, be more resilient for the future, and can even be more in touch with the needs of the community it serves.

Building a diverse board is not an easy task, and without adequate preparation beforehand organizations will not attain the full benefits of incorporating DEI commitments into the culture of the organization. Before starting this process a welcoming environment for all must be established in the organization and board room. Furthermore, clear definitions of what diversity looks like and intentional methods for achieving the vision need to be developed. Finally, organizations must acknowledge the pitfalls associated with attempts to diversify and be careful to avoid them.

Best Practices for Developing a Board DEI Committee

Methods

To guide our exploration into the creation and development of a diversity, equity, and inclusion (DEI) committee within CLL Society's Board, we asked the following question: "*What are some of the best practices for DEI committee development within a board?"* By asking this question, we were challenged with researching best practices of comparable organizations as well as the current committees within CLL Society. From these findings, we then asked, *"What would be the logistics of a DEI committee within CLL Society's Board?"* This allowed us to focus our efforts on the creation and development of a DEI committee within CLL Society as well as the task associated with this committee.

We began our approach by analyzing the CLL Society Board Bylaws for current committees and guidelines for committee creation. We also explored articles, websites, journals, and other resources for the key practices of a DEI committee. Through our research, we developed several key takeaways from DEI work within organizations as well as possible toolkits, resources, and training opportunities for CLL Society. We believe our findings and recommendations will benefit CLL Society by integrating sustainable, inclusive initiatives into their organization and board structure through the development of a DEI committee.

Findings

According to studies by McKinsey & Company, greater diversity in the workforce results in greater value creation, innovation, and performance.[220] Executive leaders looking to make strides toward a more diverse and inclusive workplace can establish actionable goals and evaluate progress by forming a DEI council or committee. Furthermore, establishing a DEI board committee can deepen the organization's commitment to diversity and keep the organization on track for accomplishing DEI goals. This requires an extensive amount of executive or high-level management commitment as well as six essential steps in creating these sorts of diverse environments. According to the US Chamber of Commerce, the six essential steps to begin developing a DEI committee are:

1. Prepare and compile the data
2. Identify community members
3. Define goals and areas of concern
4. Address policies affecting diversity

5. Implement and communicate initiatives
6. Find an ally or support system[221]

Through our research, we were able to compile these components into three primary areas of interest related to the creation and development of a DEI committee:

- Board Bylaws analysis on committee creation guidelines and restrictions
- Best practices on how to create successful DEI committees
- Beginning tasks for established DEI committees

To further understand the current committees and structure of CLL Society's Board of Directors, an analysis of the current Bylaws of CLL Society was performed (see CLL Society's Board of Directors Profile). The key takeaways from this analysis found that the Board has the power to establish three types of committees: Standing, *Ad hoc*, and Advisory. Standing Committees may be established and terminated from time-to-time and are composed primarily of Directors, while an *Ad hoc* Committee can be established and terminated at any time and may be comprised of non-Directors. An advisory committee can consist of both Directors and non-Directors but is not considered a formal committee of the Board. Persons may be elected as honorary or advisory members of the Board. Advisory members shall be those who, because of their special expertise or position in the community, can assist the Board in fulfilling its responsibilities. After a thorough analysis, we conclude that an *Ad hoc* Committee is most appropriate for the creation of a DEI committee within CLL Society, as it allows DEI experts and professionals to serve as advisors alongside Directors within a formal board committee.

Another notable takeaway from the Bylaws is the list of restrictions for each committee. The Board has the authority to grant powers to the committee as deemed appropriate. The committee does not have the power to fill vacancies on the Board, amend or repeal Bylaws, adopt new Bylaws, amend, or repeal or any resolution of the Board, and approve any contract or transaction in which a member of the Board has material interest in. Identifying the best practices for creating a DEI committee was the next task in our research.

Our research on best practices for DEI committee development revealed key steps into building sustainable and successful DEI committees. These steps can best be placed into four phases:

- Phase 1: Preparation
- Phase 2: Establishing a Framework
- Phase 3: Implementation

- Phase 4: Evaluation

These phases help guide the creation and early work of a DEI committee within a non-profit organization.[222] However, the work of a DEI committee does not stop after Phase 4. The goal is that, after Phase 4, the DEI committee should be sustainable enough to continue creating new phases and actions that lend to the overall initiative.[223]

In Phase 1, the goal is to prepare the logistical side of the committee. This is also commonly known as the pre-work of the process, which includes the composition of the committee. Studies show that the ideal number for a committee is 5-6 members depending on the overall size of the board, with the odd number being more favorable in the realm of decision-making.[224] As stated by Forbes and the University of Texas, the need for high-level management and board of directors to be a part of the DEI committee is of strong importance, as most organizations work based on a top-down framework.[225, 226] The next steps of this phase include assessing the knowledge, and/or lack of knowledge, of both board members and committee members. Best practices state that the only way to truly understand DEI initiatives is to have a strong understanding and knowledge of DEI principles. Therefore, training and education on DEI principles and terms should be conducted. This will be discussed further in the next chapter of the report on DEI training and professional development for the Board.

Phase 2 is where the DEI committee and the organization collaborate. Our research emphasizes how members of the DEI committee should spend a considerable amount of time in their first meetings defining the purpose, expectations, goals, and possible outcomes of the committee. Studies show that having clarity in definitions and expectations leads to great performance and productivity. Research states that to be the most effective these definitions must merge and align with the organization’s missions, values, and goals for there to be true integrations. In some instances, this requires organizations to make amendments to their previous mission and vision statements. According to research, a DEI plan that outlines where improvements can be made in the organization’s staffing, and even in volunteers, better serves the organization’s mission. Another best practice to consider is the concept of safety within the committee as well as within the organization. Although DEI committees are developed for the purpose of promoting DEI within the organization, they are not always seen as safe spaces to communicate, especially if their ideals are not held by committee members. Thus, establishing guidelines or rules that promote safety within the committee is an important step that should be included in the committee’s plans.[227]

Phase 3 considers the best practices for developing DEI initiatives and actions that will begin the work of the committee. The Office of Inclusion and Equity at the University of Texas at Austin emphasizes the need for the development of a diversity planning process. In this process, the committee adopts a planning process and develops a timeline for addressing the critical issues in need of attention. The committee begins by identifying and confirming their overarching purpose and by establishing guidelines to help with their intended goals set in Phase 2. From there, the committee should begin brainstorming action steps for achieving individual initiatives. Lastly, the committee should work to establish budgets and plans to implement these initiatives within the organization and community they serve.[228]

The emphasis of data collection and analysis is the driving force behind Phase 4. It is equally as important to evaluate the progress of the committee as it is to create diversity initiatives. This helps ensure that the work being done is impactful and effective. The best practices for this phase are to create measurable criteria, such as benchmarks, for the goals of the initiatives set forth by the committee. Another best practice for this phase is to develop ways of assessing the success of each initiative and analyzing the data gathered from those assessments. This requires knowledge of data analytics and how to compile and present results to both the committee and the Board of Directors.

Each of the four creation phases are equally important, and they help identify the tasks held by the committee. Looking at the importance and impact of intentional DEI tasks, our research revealed notable takeaways. When thinking about the tasks of a DEI committee, it is important to realize the value in new beginnings. As this is the beginning of a new committee within CLL Society, the focus and tasks of the committee should deal with both the internal needs of the committee and board structure as well as the external needs of the community it serves.

To lead the organization and serve the community, one cannot develop a DEI committee without clear understanding and acknowledgment of one’s own potential knowledge gaps intentionally and effectively. Therefore, steps like determining a budget for the diversity initiative, establishing, and clarifying the commitments and the expectations of the participants, assessing the knowledge or lack of knowledge of the committee members and board members on DEI initiatives, and undergoing DEI training are suggested best practices for establishing a DEI committee. It is also important to ensure that board members and staff learn as much as they can about DEI principles to achieve buy-in and to ensure the goals of the committee match the organization’s internal and external needs.[229]

From our research, large businesses, and enterprises, like Forbes, emphasize the need for DEI committees to define their framework and their purpose.[230] The TSNE MissionWorks organization states that building a definition or substantive framework will help the nonprofit build and reinforce the commitment to the diversity initiative it is trying to implement. There are multiple key components to the success of any definition of purpose, such as clearly articulating the philosophy in the mission for diversity and how it connects to the mission of the organization as well as clarifying and teaching terminology related to DEI and cultural competence.[231] The Pillar Nonprofit Network's *Board Diversity Training: A Toolkit* emphasizes how trainings can help guide committee and board members with everything from acknowledging DEI principles to implementing actionable steps towards achieving them.[232]

Finally, in our research, there was an emphasis on the long-term goal of ensuring recruitment and retention of diversity inside the organization. At the same time, facilitating cohesion and understanding among the existing board members and new recruits is essential. These two concepts come together to create a comfortable space by ensuring that all members, old and new, are on the same page about the intentions of their diversity initiatives and incorporating them into the organization's mission, values, and operations.

Conclusions

The creation and development of a DEI committee within the board of any organization is one that challenges the current makeup of the organization. To be successful in the creation and the development of such a committee, there are many steps that must be taken into consideration. Through our research, we found that the best practices for developing a DEI committee involve intentional actions throughout the implementation process. The four phases dealing with preparation, establishment of framework, implementation of initial DEI initiatives, and the evaluation of these initiatives are of particular importance. When developing a planning process, existing best practices should serve as a guide to ensure the effectiveness and cohesiveness of the committee. While DEI committees will differ for every organization, the beginning framework should remain similar for the best chance of long-term sustainability and effectiveness. Our recommended steps for CLL Society in developing a DEI Committee are presented in Appendix B.

Best Practices for Board DEI Training and Professional Development

Methods

To guide our exploration into possible DEI training for CLL Society's Board of Directors, we asked the following question: "*What are some of the best practices in board professional development surrounding diversity, equity, and inclusion?"* Instead of focusing specifically on either creating a training or searching for possible training opportunities, we developed this question to expand our scope and explore insight and existing knowledge from other organizations committed to DEI work.

By taking this qualitative approach to our research, we explored articles, websites, blog posts, and other available resources and insights. Through our research, we came across key takeaways within the field of DEI work for organizations as well as possible toolkits, resources, and training opportunities for CLL Society. Our findings and recommendations provide opportunities for CLL Society to engage with and implement its internal and external DEI commitments among its Board of Directors more fully.

Findings

Through our research, we settled on two primary areas of interest related to board training and professional development:

- The importance and impact of DEI trainings and professional development on board and organizational performance
- Best practices when providing these opportunities to a board of directors

Looking at the importance and impact of training and professional development, our research revealed several notable takeaways. A recent study conducted by Johnson, Grossnickle and Associates; BoardSource; and the Indiana University Lilly Family School of Philanthropy found that having tough conversations around diversity, leveraging engagement, and fundraising, and fostering a culture of continuous learning are important actions to move towards increasing board engagement. All three of these actionable areas require attentiveness to skill-building and being deeply engaged with the issues of the organization. In addition, this level of engagement and investment in individual board members allows for added value and leadership as board members contribute to and collaborate within a shared learning environment.[233]

Similarly, the Coalition for the Delaware River Watershed's *Diversity, Equity, Inclusion, and Justice Toolkit* details the importance of DEI training and professional development in building a culture of continuous learning and engagement. They find that DEI training and development help individuals and communities to overcome fear and anxiety around DEI topics and issues. Exposure to this kind of continued education and awareness builds cultural competency, cultural humility, community engagement, and even more effective partnership building for organizations.[234] According to Eric Ellis, president, and CEO of Integrity Development Corps, engaging and communicating about DEI principles requires training and practice. People can only recognize the need for and importance of DEI work if they have engaged with their personal journey in some way.[235]

By investing in a culture of continuous learning and engagement, DEI training and professional development can also help influence overarching board culture. In the same way that creating a board manual, orientation program, board member self-evaluation, or a board meeting evaluation builds a particular culture of board practices, providing regular DEI training or professional development can also influence that culture of best practices.[236] The Minnesota Nonprofit Association's Diversity, Equity, and Inclusion Assessment argues that DEI assessments are important ethically, economically, and organizationally to influence this culture-building. While all organizations move around on the continuum of best practices, engagement with DEI principles on multiple levels will help build more inclusive governance practices.[237]

In *Moving to Transformational Inclusivity and Board Diversity*, Fredette, Bradshaw, and Inglis identify two pathways to inclusion that help illustrate the impact of inclusive culture within a board of directors. First, functional inclusion is when organizations recognize and work towards representation of diverse backgrounds in membership alone. While important to the overall work, functional inclusion alone can lead to tokenism. On the other hand, social inclusion, or helping board members form and strengthen relational bonds with one another, builds a stronger board culture. This social inclusion includes mentoring, programs, retreats, training, and other professional development opportunities to build a culture of inclusion in place of reinforcing tokenism.[238]

DEI training and professional development can also impact overall organizational performance. BoardSource's 2017 *Leading with Intent* study found that boards influence organizational performance in two major ways: through understanding board roles and responsibility, and through the board's ability to work collaboratively with one another. Assessing both board performance and organizational performance is a part of professional development, but only 37% of organizations budget for board professional development in this way. Furthermore, only 21% of all nonprofit organizations have conducted diversity training for their staff and board. Board members are more likely to engage in self-reflection when given opportunities to connect with and learn from one another through intentional training and professional development. Providing space for this kind of capacity-building also influences stronger organization-wide performance.[239] In each of the above ways, training and professional development for board members creates valuable internal shifts towards increased organizational culture-building, engagement, and performance.

Looking at best practices in providing DEI-related training and professional development, we also came across several areas of interest for providing these opportunities. First, we found that DEI training and professional development, while incredibly important, should not be viewed as an isolated or one-off activity. The Pillar Nonprofit Network's *Board Diversity Training: A Toolkit* emphasizes the importance of seeing training and education as part of long-term strategies towards organizational change. These initiatives should help board members move from simply acknowledging DEI principles and commitments to acting out those principles in both governance practices and in relationships with one another.[240] Organizations must also recognize the difference between trainings, self-assessments, and other professional development opportunities that focus on specific topics such as power, privilege, and oppression. Diversity training alone does not change attitudes towards minority groups or provide many tools to apply learning in action, and therefore should not be the primary focus of DEI efforts. However, training should still be treated as a necessary part of the ongoing commitment to organizational change.[241,242] In other words, these practices are crucial, but not the be-all-end-all in DEI work.

We also found that these efforts are most effective when approached from both short-term intensive and long-term ongoing access to resources, conversations, and thinking about organizational structures. While basic 101 training for board members (and staff) can be beneficial early on, organizations should plan to deepen their DEI training over time, providing continuing education and skill-building in a variety of different ways.[243,244,245,246] These practices can include activities such as taking implicit bias tests and discussing the implications of that learning; sharing DEI resources at board meetings; providing both internally-led and externally-led trainings or conversations around DEI topics including changing demographics, diversity language, cultural competency, case studies, racism in organizations and communities; and even organizational change processes.[247,248] By providing this breadth of training and professional development opportunities, organizations can more effectively and appropriately create inclusive environments.

While the above suggestions are all important ways to engage with DEI work in both the short and long-term, the most effective trainings and development opportunities include facilitated discussions that create space for power-sharing among participants while not forcing vulnerability for individuals from marginalized groups.[249] These discussions and spaces can and should be guided by both internal and external leadership, as appropriate. When choosing an external consultant or trainer, organizations should recognize the importance of learning from and compensating people who identify as Black, Indigenous, and/or people of color (i.e., BIPOC). Our research found that hiring all white consultants and trainers continues to center whiteness by seeking to make white people more comfortable in a training setting.[250] Organizations must recognize the differences between hiring outside experts for actual intentional change-making or simply for “looks” and attempting to appease white people (whether as participants, supporters, donors, or other roles).[251]

External guidance from BIPOC can be incredibly helpful for conversations and trainings, but organizations need not depend on outside consultants and facilitators for all professional development activities. Internal leadership can also build capacity among board members by engaging with DEI topics more informally through regular conversation or the use of self-assessments designed to be internally-administered.[252] Training alone from outside experts cannot be the destination because individuals come from vastly different backgrounds of language, knowledge, and awareness around DEI work that cannot be transformed solely through training.[253] Providing internally-facilitated dialogues or assessments can help mediate these challenges with trainings while still engaging with the work in a meaningful way.

Through our research, we also found that DEI training and professional development should be treated as highly important for all board members. These opportunities should be included in board orientation and throughout normal board practices.[254] Requiring or incentivizing participation in training or development opportunities can again build organizational culture. Encouraging participation helps develop a shared understanding among board members of DEI commitments and values and a shared framework for thinking about organizational systems and structures.[255] Additionally, if all board members participate in these opportunities, it sends a message of commitment to the entire organization, further expanding the impact of DEI values and encouraging participation from more people.[256]

Finally, as noted above, the overwhelming “best practice” for DEI training and professional development is to embrace the long-term nature of the work. Creating a culture of inclusion takes time and requires the ongoing commitment to setting standards, evaluating progress, reflecting on changing needs, and providing continuous professional development opportunities to board members, staff, volunteers, and stakeholders.[257] Again, training alone cannot and should not be the final goal of implementing DEI values in the workplace. Focusing solely on training only serves to continue centering whiteness and white culture within the workplace.[258] However, embracing training and professional development as a necessary part of building more inclusive work environments allows organizations to invest in stronger governance practices and overall board engagement.[259]

In addition to our overall findings, we recommend consulting the following list of organizations that can provide future training and professional development for CLL Society’s Board and staff. Each organization’s offerings are detailed more fully in the Partnerships section of our broader report:

- National Equity Project
- BoardSource
- The Participation Company

Conclusions

While DEI training and professional development for nonprofit boards are incredibly important for overall organizational progress, they can also be problematic if approached ineffectively or only for looks rather than real organizational change. Through our research, we found that training and professional development opportunities can help individuals and organizations to improve performance, build stronger relationships, and engage in transformative work to build more inclusive cultures. When providing DEI training and professional development, organizations should recognize existing “best practices” to make these opportunities more effective, equitable, and actionable. While not a solution to all DEI issues, training and professional development are necessary to overall organizational change-making and systemic transformation.

Recommendations

Recommendation #1: Diversity Recruitment

To incorporate more diversity onto the CLL Society Board of Directors, we recommend for the organization to act on the following:

Thoughtfully analyze the current board and organization culture with a focus on how welcoming it is to diverse perspectives.
Ensuring a positive and welcoming environment is present increases the likelihood that new members will quickly find their place on the board and develop a deep commitment to the mission that makes them want to stay long-term.[260, 261]

Conduct an assessment of current board skills and demographics.
This assessment should go beyond race and other demographic features to include personal background, professional expertise, and any relevant skills. It should not be thought of as a checklist for what identities should be recruited, but rather as a useful guide for skills and perspectives that would be beneficial to CLL Society’s Board.[262, 263] The Board of Directors Profile included in this section of the report is a good starting point for this.

Define what a diverse board looks like and means for CLL Society.
All board members should engage in discussions around the meaning of DEI in order to enhance buy-in and understanding of how diversifying the board will be beneficial to the organization. Creating diversity statements and posting them publicly can also show potential board members the organization’s commitment.[264, 265]

Know the exact reasoning behind why you are recruiting an individual and the specific skills and value they will bring to the organization.
The organization should expect that prospective board members will want to know why they are being recruited and what they have to offer the organization. If the organization does not have an answer beyond fulfilling a diversity goal, they are at risk of making the individual feel tokenized.[266]

Expand recruitment searches beyond the current network of board members and organizational staff.

Simply working within existing networks of the organization only reinforces present diversity issues. Seeking out individuals involved in other community-based organizations can help identify prospects with different expertise and points of view.[267, 268]

Monitor and evaluate the impact that increased board diversity has on CLL Society's mission and strategic goals[269]
Tracking the retention rates of new members and conducting self-assessments with all board members can show how successful diversification efforts have been and illuminate areas for improvement.[270]

Recommendation #2: Diversity Training

For board DEI training and professional development, we recommend that CLL Society commit to creating a culture of inclusion where the Board of Directors:

Recognize that DEI-related training and professional development is necessary for all staff and the entire Board of Directors.
Continued training and professional development is crucial to the long-term success of building inclusive cultures and transforming organizational structures. Additionally, DEI training for staff and the Board should not be treated as an isolated or one-time-only activity.

Choose one DEI training from an external organization to budget for in 2022.
At a minimum, this training should be for Board members, but we also recommend considering including staff in this training. As outlined in the Partnerships section of our report, we recommend choosing a training opportunity from the National Equity Project, BoardSource, or The Participation Company. Moving forward, we recommend budgeting for at least one training a year, ideally on different topics and skill-building.

Commit to regular discussions of DEI topics at Board meetings.
To expand professional development around DEI awareness and education, engage in regular DEI professional development for Board members. At a minimum, *every other* Board meeting should include a conversation about an article, blog post, assessment tool, or other resource related to DEI work either individually or organizationally.

Create a list of articles, blog posts, assessment tools, and other resources for internal professional development use by Board members.
Consult this list in preparation for Board meeting discussions or for use at any other time by Board members, as needed. If creating a DEI Board Committee, assign this

task to those individuals, otherwise create a collaborative document to collect and track the use of these resources as a team.

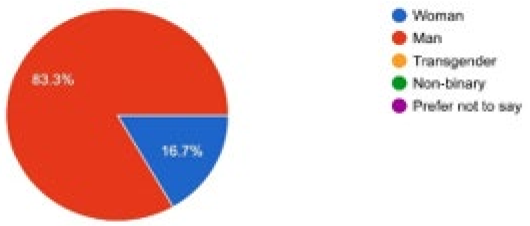
Commit to hiring a DEI consultant in 2-3 years.

This consultant can guide both reflecting on existing efforts to build inclusive cultures at CLL Society and operationalizing a long-term strategy for continued DEI capacity-building within the organization. By putting off this consultation for a few years, CLL Society can begin implementing recommendations from this plan and invest in continued reflection and guidance in the future.

Appendix A: CLL Society Board of Directors Diversity and Inclusion Survey Results

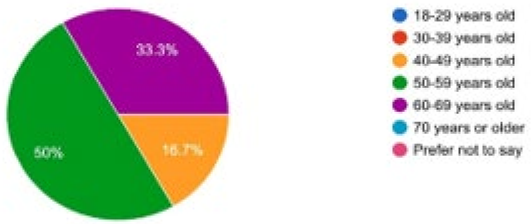
Question 1

What is your gender identity?
6 responses



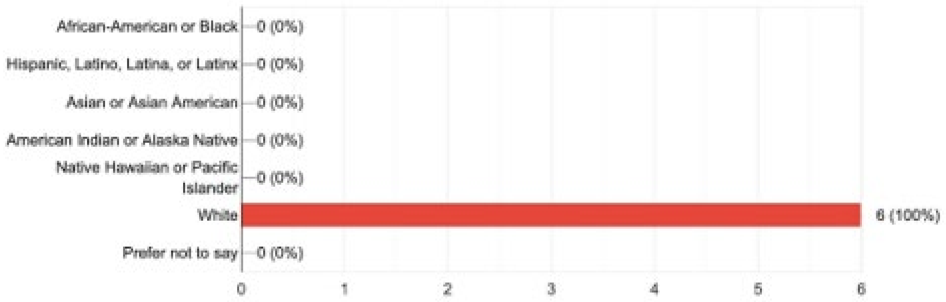
Question 2

What is your age?
6 responses



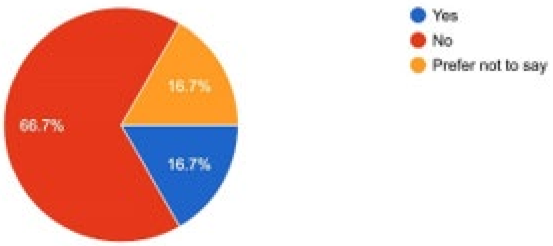
Question 3

What is your racial or ethnic identity? (select all that apply)
6 responses



Question 4

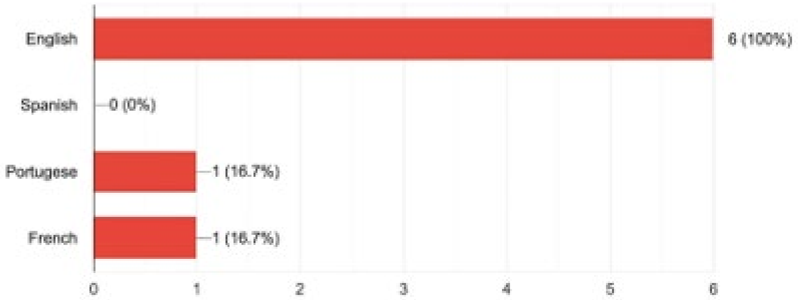
Do you have a disability?
6 responses



Question 5

What language(s) are you capable of speaking fluently? (select all that apply)

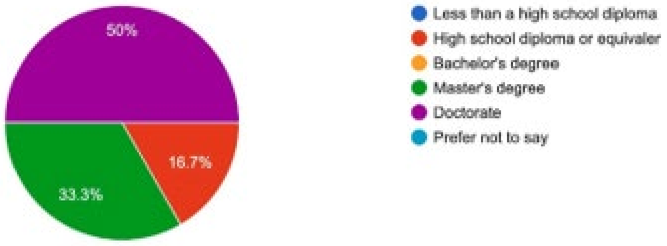
6 responses



Question 6

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

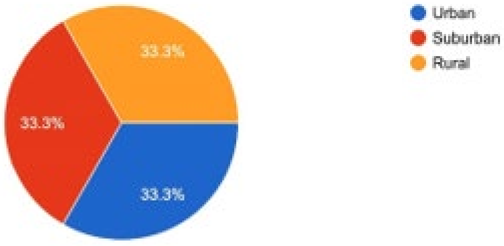
6 responses



Question 7

Which of the following best describes the area you live in?

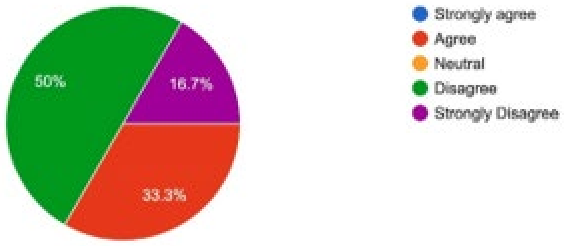
6 responses



Question 8

There is cultural diversity among the board members of CLL Society.

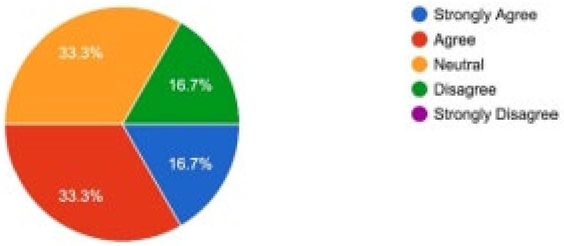
6 responses



Question 9

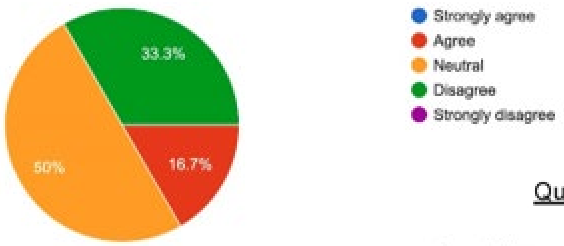
Society has done a good job promoting diversity and inclusion within the organization.

onses



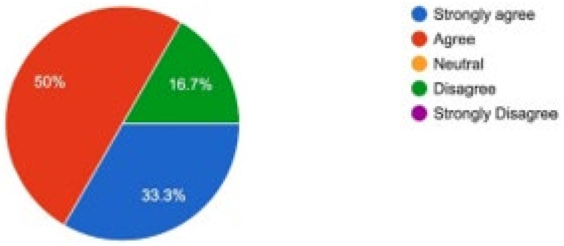
Question 10

CLL Society has done a good job providing training programs that promote diversity and inclusion.
6 responses



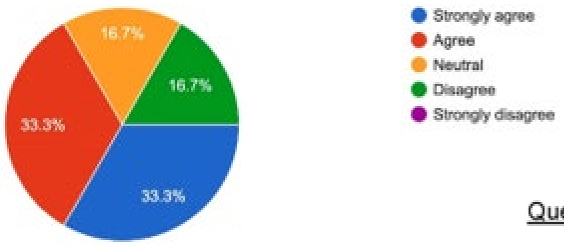
Question 11

I would like to see diversity, equity, and inclusion training programs made available for CLL Society employees and board members.
6 responses



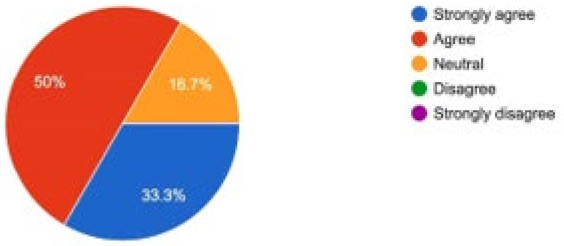
Question 12

I would be open to attending diversity, equity, and inclusion-related trainings for CLL Society employees and board members.
6 responses



Question 13

I would be open to incorporating a Diversity, Equity, and Inclusion committee into CLL Society's board.
6 responses



Question 14

In what ways do you believe diversity could be improved on the Board?

Response 1 of 2: "Good to see where we are now with 5 employees. Something to think about if we get bigger. Priority #1 is on CLL patients."
Response 2 of 2: "How diversity affects CLL patients"

Appendix B

Building a DEI Board Committee

RECOMMENDED STEPS FOR IMPLIMENTATION

Committee Creation via Constitution & Bylaws

- Proposal of DEI Committee as an Ad-Hoc Committee of the Board
- Board discussion and vote
- Board establishment of authority given to the DEI Committee (if vote approved)

Phase 1: Preparation

- Committee composition recommendations
    - Member Quantity - maximum 5 members partially comprised of both Board members and non-board community DEI members
        - Board of Directors
        - Community member recommendations
            - Proposal and vote via Board President and Board members
- Determine committee meeting frequency & structure
- DEI assessment of Board and Committee Members
- DEI training of Board and Committee Members
- Education of DEI terminology

Phase 2: Establishment of Framework

- Define what the purpose of a DEI Committee is for CLL Society
- Define roles and expectations of committee members
- Define what DEI looks like in the CLL Society
- Define DEI initiatives (goals) for the Committee and CLL Society
- Discuss possible expected outcomes

Phase 3: DEI Initiative Implementation

- Define & discuss initiative
- Present DEI initiative
- Define action steps
- Implement initiative steps
- Repeat

Phase 4: Evaluation

- Define criteria for measurement of implementation
- Analyze implementation
- Present evaluation findings

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Conclusion

CLL Society wanted to ensure that all patients have access to the best possible care, regardless of race, geography, and/or other socioeconomic factors. Further, they were interested in strengthening their DEI initiatives, as well as advocating for equitable access to quality care and elevating the patient voice in all stages of CLL management. We were given seven key focus areas to help the CLL Society achieve this goal. These focus areas included: literature review, clinical trials, community outreach, CLL Society brand review, partnerships, environmental scan, and board development. A literature review was conducted to uncover the disparities that exist within CLL and identify underserved communities. Clinical trials then developed a plan to improve messaging around clinical trials, to overcome issues of mistrust, and to help communities understand the benefits of clinical trials. Community outreach developed a plan to specifically connect with the African American communities, as well as identify other underserved populations to help raise awareness of CLL and provide these underserved communities with beneficial resources and support. CLL Society brand review evaluated the current CLL Society messaging and imagery to ensure diversity and inclusiveness. Partnerships then identified other organizations with whom the CLL Society could partner with to provide information and resources to underserved communities identified by community outreach. Environmental scan researched similar organizations to uncover effective strategies and tactics to integrate diversity, equity, and inclusiveness into their organizational mission that could then be applied to the CLL Society. Finally, board development developed a plan for recruiting Board members who would expand the CLL Society's representation.

While these were the central components of our paper, we provided additional resources, guides, and recommendations that we believed would be beneficial for future DEI initiatives within the CLL Society. Within these focus areas we conducted research, outlined best practices for the CLL Society moving forward, and provided our final recommendations. We believe that the extensive amount of research, resources, and recommendations we provided the CLL Society will help them achieve their goals of providing equitable access to quality care.