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Evaluation of the Leukemia & Lymphoma Society (LLS) Myeloma Link Pilot Program

Executive Summary

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Prepared for: The Leukemia & Lymphoma Society (LLS)/
The National Black Church Initiative

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Executive Summary

Overview

The purpose of the Myeloma Link Pilot Program was to implement a church-based initiative in black communities, particularly low-income communities, in an effort to: 1) heighten awareness of myeloma; 2) increase knowledge about the disease and treatment; 3) provide information and resources that will empower patients to seek novel treatments and enroll in clinical trials in a timely manner, and 4) encourage patients and caregivers to use a new, sustainable support infrastructure. The National Black Church Initiative (NBCI) was a key partner in this pilot.

The National Black Church Initiative (NBCI) is a coalition of 34,000 African-American and Latino churches working to eradicate racial disparities in healthcare, technology, education, housing, and the environment. NBCI's mission is to provide critical wellness information to all of its members, congregants, churches and the public. The National Black Church Initiative's methodology is utilizing faith and sound health science.

The aim of the initiative is to offer our member congregants and the public helpful and healthy science-based tips on how to develop and maintain a healthy lifestyle. The website also offers the latest information on housing, education, technology and environmental issues.

The National Black Church Initiative's purpose is to partner with major organizations and officials whose main mission is to reduce racial disparities in the variety of areas cited above. NBCI offers faith-based, out-of-the-box and cutting-edge solutions to stubborn economic and social issues. NBCI's programs are governed by credible statistical analysis, science-based strategies and techniques, and methods that work.

The Myeloma Link pilot activities were implemented in Atlanta, GA and Washington, D.C. between March, 2017 and May, 2018. They focused on the general population as well as members of key churches, interested community members, and myeloma patients and caregivers. These populations were reached with a variety of activities including: 1) Media activities and events, 2) Church-based awareness building events; 3) Education programs (general awareness, topic-specific, in-depth Myeloma 101); 4) Myeloma Ambassadors; 5) the creation of a Directory of Resources and Cancer Centers; and 6) a Support Group Needs Assessment.

This is a summary of the results of an evaluation that was conducted on the Myeloma Link program by Shattuck and Associates (S&A), an independent program planning and evaluation firm, with the support of LLS. S&A, in collaboration with LLS, conducted surveys to evaluate Myeloma Link activities including: Myeloma Sundays, Fellowship Hours, Topic-Specific Education Programs, and Awareness Education Programs. In addition, in-depth interviews were conducted with project staff, Myeloma

Ambassadors, and community support participants (CSPs) who were involved with planning and delivering Myeloma Link activities. Finally, S&A supported LLS in tracking Myeloma Link events and community interactions as well as media outreach.

Methods

The evaluation examined process and outcome questions that were designed to help LLS evaluate the activities and to better understand how findings from the pilot project can be used to improve, expand and sustain the project in the future. Specific methods used to answer these questions included:

- Myeloma Sunday Surveys (96 in D.C., 434 in ATL)
- Fellowship Hour Surveys (55 in ATL)
- Topic-specific Education Program Exit Surveys (36, 2 programs in D.C. only)
- Awareness Education Program Exit Surveys (23 in D.C., 198 ATL)
- In-depth Education Program Pre and Post Surveys (24 Pre, 20 Post, 16 Both)
- In-depth interviews with LLS staff members, ambassadors and community support participants (CSPs) (n=10)
- Tracking of outreach events through the use of event cover sheets completed by program coordinators
- Tracking of outreach activities and two-way interactions with churches and other organizations using Salesforce
- Short surveys completed by ambassadors to evaluate the First Connection component of their training (n=5)

Process Evaluation Summary of Key Findings

Process evaluation questions focused on the characteristics of Myeloma Link program participants, how participants interacted with the program, the participants' experiences with the program activities, and suggestions for improving and sustaining Myeloma Link in the future.

Characteristics of the participants of the LLS Myeloma Link Project

- Survey findings showed that overall, most participants in the Myeloma Sunday and In-depth Education Program were:
    - Not myeloma patients or caregivers
    - Older than 55, Female, Black or African American
- Participants in the Topic-Specific Educations Programs were more likely to be:
    - Cancer patients or caregivers with (60%) in the Therapies Education Program and 6% in the Survivorship reported having myeloma; More even split between male and female participants
- Ambassadors included:
    - Five volunteers participated in the LLS First Connection Training and became ambassadors (3 in D.C., 2 in ATL)
    - Four of five ambassadors were female and three were patients or caregivers

Participants' interaction with the Myeloma Link activities

- The Myeloma Link project included a total of 26 Myeloma Sunday Sermons (17 in Atlanta, 9 in D.C.) and 16 education programs (12 in Atlanta, 4 in D.C.).
- In addition, several other types of outreach activities, including media events, took place in both cities reaching over 4000 people in the target population.

Myeloma Link Participants' experiences with the outreach activities

- Overall, survey participants expressed satisfaction with Myeloma Link events and activities.
- Participants were generally engaged in the activities, especially participants of the education programs.
- All interviewees felt that participants were generally satisfied with the activities. In addition, CSPs expressed personal satisfaction with their involvement in Myeloma Link.
- Staff felt that the Myeloma Link activities provided value to participants in terms of raising awareness and being proactive in their health care; they felt the education programs were particularly valuable for patients.
- While ambassadors serve as an important link to the myeloma community, there is a need to clarify their role and balance their workload.
- While some churches were open to the Myeloma Sundays, other churches were less receptive to incorporating health messages into Sunday worship services.

Participants', Staff and Ambassadors Suggestions for Sustaining and Improving Myeloma Link in the future

- Most suggestions related to strengthening partnerships focused on relationship building and networking with organizations beyond churches, improved program promotion/public relations for LLS and Myeloma Link, and increasing community presence.
- Interviewees provided suggestions related to reaching Black and African American patients in addition to the current approach of targeting churches. Recommendations centered around connecting with health care providers and other community organizations as well as increasing media activities and connection with Black stakeholders in the community.
- Staff recommendations focused on expanding the project beyond churches, delivering more education programs, re-examining the volunteer structure and creating outreach tools so the project can be more self-driven.
- Ambassadors recommended utilizing ambassadors for participant recruitment, and improving system of communication with churches before the Myeloma Sundays.
- CSPs suggested improving and updating educational materials and making changes to the Myeloma Sunday Sermon (e.g. offering evening session, increase the length of the health sermon).

Outcome Evaluation Summary of Key Findings

Outcome research questions examined changes in participants' awareness of available resources, awareness and knowledge of myeloma, diagnosis and treatment. CSPs and ambassador were asked to provide feedback about increasing social support and disease management skills/behaviors.

Awareness of LLS resources

- Overall, Myeloma Link Program participants reported increased awareness of myeloma and LLS resources. Likewise, participants in the in-depth program showed knowledge gains related to myeloma.
- Based on feedback and their own observations, ambassadors and CSPs felt that participants experienced an increase in awareness and knowledge of LLS resources and myeloma, particularly as a result of the education programs.
- All CSPs reported a significant increase in their own knowledge and awareness of myeloma and diagnosis, treatment and resources for persons with myeloma.

Suggestions for improving and increasing social support and skills/behaviors

- Suggestions for improving social support among Black and African-American myeloma patients/caregivers in the community included the promotion and dissemination of LLS resources, connection of patients with health care providers, social workers, and other resources including support groups at local churches.
- Suggestions for how to help myeloma patients increase skills/behaviors to navigate treatment to more effectively cope with their disease included continued communication, education and empowerment so patients can reach out to health professionals and other patients for the appropriate support.

Conclusions and Recommendations

Overall, the evaluation showed many positive outcomes for the Myeloma Link Pilot Project, while also identifying certain areas that could be targeted for improvement. Over 4,000 people in Atlanta and D.C. were reached by Myeloma Link activities, and in general, Myeloma Link staff and participants reported high levels of satisfaction, particularly with the education programs. Participants of the Myeloma Sundays and Education Programs reported overall awareness and knowledge gains. Moreover, there was a 46% percent increase in myeloma related calls to the IRC in Atlanta, which far outpaced the national increase of 17%.

Several challenges were noted with respect to delivering the Myeloma Sundays through churches, especially during worship hours. Some useful recommendations for improving the program were provided by interviewees related to broadening reach to patients, re-examining the role of volunteers and ambassadors, expanding promotion of the program, and increasing the number of education programs delivered. It is recommended that LLS review all individual suggestions and consider improvements in the following areas:

- Expand the process of partnering with churches (e.g. create a LLS presence in the community before the program, offer programs outside of the worship time, partner with organizations of church leaders);
- Maximize word of mouth marketing for Myeloma Link by identifying and connecting with key influencers in the target population, connecting with the community, and eliciting feedback from participants and community members throughout the program
- Expand the marketing campaign with traditional and social media activities
- Develop a more consistent and streamlined tracking and data collection system
- Connect with health care providers and organizations and implement more education programs to expand the reach of Myeloma Link to myeloma patients and caregivers.

Information and recommendations offered by the participants in this evaluation provide LLS with useful information on ways to expand the Myeloma Link program and reach African American myeloma patients and caregivers so they are informed, supported and have and have the resources they need to manage and treat myeloma.