1100 – Clinical research in SLE

1101 USE OF POPULAR OPINION LEADER MODELS TO DISSEMINATE INFORMATION ABOUT CLINICAL TRIALS TO PEOPLE OF COLOR WITH LUPUS IN TWO U.S. CITIES

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Background Despite a disproportionate burden of SLE and disparities in adverse outcomes among Black compared to white individuals, people of color are underrepresented in SLE clinical trials. Our aims were: (1) to leverage a community-academic partnership to develop clinical trial education modules for individuals who self-identify as Black with SLE and (2) to recruit and train trusted Popular Opinion Leaders (POLs) with robust social networks to disseminate this information. Due to COVID-19, we adapted the traditional, in-person, POL model to a virtual platform and assessed feasibility.

Methods Academic and community leaders in Boston and Chicago developed training modules about clinical trials. POLs age ≥18 years old with and without SLE were recruited through community- or hospital-based networks from Boston and Chicago neighborhoods. To train the POLs, five presentations were delivered using an interactive, virtual platform. Modules included: (1) Description of the POL Model, (2-3) Introduction to Clinical Trials, I/II, (4) History of Racism and Clinical Trials, and (5) Clinical Trials: Barriers, Facilitators, and Mediators. POLs completed pre and post-tests, which were compared using paired t-tests. POLs were taught to use virtual platforms to share information learned with their social networks and reported their dissemination.

Results Nineteen POLs were recruited in Boston and 17 in Chicago (table 1). In Boston, 18 (95%) were female, 13 (68%) self-identified as Black, and mean age was 55.6 years. In Chicago, 14 (82%) were female, 16 (94%) self-identified as Black, and mean age was 52.8 years. Retention of POLs throughout the training was 82% both cities. For the two-part clinical trials module, POLs' knowledge of clinical trials improved significantly (mean difference of 3.92 points, 95% CI 3.35-5.89). As of May 2021, 7 POLs documented 36 encounters and reached 1,023 total individuals; dissemination is ongoing. Boston POLs reached 233 people, including 122 individuals through a sorority newsletter, 104 through Zoom, 6 through phone calls, and 1 in person. Chicago POLs personally reached 240 individuals, including 163 people in a social media group for SLE patients and families, as well as 550 individuals through email interactions.

Conclusions The POL model was effectively adapted to a virtual program in the context of COVID-19. Modules developed jointly by academic and community partners were implemented and successfully improved knowledge regarding clinical trials. POL retention was high, possibly due to the convenience of virtual trainings and the sense of community developed. Further studies are needed to determine impact on the diversity of SLE trial enrollment.

Abstract 1101 Table 1 Characteristics of Popular Opinion Leaders in Boston and Chicago

Site	Boston	Chicago
Number of POLs	19	17
Mean (SD) Age	55.6 (11.4)	52.8 (18.2)
Sex – N (%)		
Female	18 (95)	14 (82)
Male	1 (5)	3 (18)
Self-identified Race/		
Ethnicity- N (%)		
Black/African American	13 (68)	16 (94)
White	3 (16)	0
Other Race	2 (11)	0
Hispanic	1 (5)	1 (6)
Educational attainment		
(%)		
High School	6 (32)	1 (6)
Technical School/GED	3 (16)	2 (13)
Bachelor	4 (21)	6 (38)
Master	6 (32)	3 (19)
Mean Years of Work Experience (SD)	28.8 (13)	27.4 (10)
Marital Status (%)		
Single	11 (58)	7 (41)
Married	4 (21)	6 (35)
Divorced	3 (16)	2 (12)
Widowed	1 (5)	2 (12)
Housing (%)		
Live with spouse, blood relatives and family	10 (53)	10 (59)
Live alone	9 (47)	7 (41)
Health Conditions (%)		
Diagnosed with lupus	12 (63)	13 (77)
Diabetes	1 (5)	0
Hypertension	7 (37)	9 (53)
Arthritis	12 (63)	12 (71)
Obesity	9 (47)	4 (24)
Relative with lupus (%)	8 (42)	11 (65)
Previous Community-		
Based Experience (%)		
Previous training as a health promoter	8 (42)	3 (18)
Participated in previous lupus educational training	13 (68)	13 (77)
Hosted presentations or community-based events	11 (58)	9 (53)
Gave testimony	10 (53)	5 (56)
Presented at health fairs	8 (42)	8 (89)
Distributed educational materials	10 (53)	8 (89)
Contacted stakeholders	6 (32)	3 (33)
Participated in patient advocacy	9 (47)	4 (44)
Collected information from community members (surveys or other)	6 (32)	3 (33)
Patient navigation	5 (26)	3 (33)
Social Network (%)		
Member of a gym/sports club	7 (37)	8 (47)
Member of a faith-based organization such as a church or ministry	11 (58)	13 (77)
Have places they meet with their social network	10 (53)	8 (47)

Abbreviations: POL, Popular Opinion Leader; GED, General Educational Development.