RARE CAMELLIAS: A study in the feasibility of a hybrid virtual platform support system in expanding accessibility of gynecologic oncological clinical trials to rural Louisiana

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BACKGROUND

Rural Americans continue to face disparities surrounding the burden of cancer incidence and mortality, largely driven by unequal access to specialized cancer care, especially clinical trials. This burden is specifically evident in Louisiana, where nearly *two-thirds* of parishes are classified as rural and *one-third* of the population resides in a rural area. On average, urban communities have access to more than eight times as many specialists per 100,000 than their rural counterparts. Access to gynecologic oncologists is particularly limited with only 10% of women in the United states living within a 50-mile radius of one, compounding barriers to timely and specialized treatment even further. Clinical trials play a critical part in not only developing innovative medical treatments but also in creating optimized standards of patient care. Cancer patients who participate in clinical trials are shown to have better progression-free and overall survival, highlighting the need to expand trial accessibility among underserved rural populations.

Barriers in rural oncologic clinical trial participation:
Rural communities in the United states have limited access to comprehensive cancer centers, lacking the infrastructure often needed to conduct clinical trials, therefore patients must often travel outside their community to have the option to participate in clinical trials. This leaves the burden of time and cost of travel on patients and their families.

The **RARE CAMELLIAS** (viRtual plAtfoRm to improvE Cancer cAre, coMmunity outrEach and cLinicaL trIAl enrollment) program offers a novel solution through a hybrid model that integrates centralized trial coordination with decentralized follow-up care, partnering community health care with research infrastructure, directly addressing the burdens rural residents face in accessing clinical trials. Distinctively, this study integrates patient and provider perspectives to offer a dual lens on access and experience in cancer trial participation.

OBJECTIVES

Aim 1: Assess the feasibility of integrating virtual surveillance and follow up procedure using a centralized university clinical trial system.
Aim 2: Depict RARE CAMELLIAS participant satisfaction.
Aim 3: Describe provider professional fulfillment and burnout experiences with the RARE CAMELLIAS program.

METHODOLOGY

A retrospective chart review of a single clinical trial was conducted, comparing RARE CAMELLIAS protocol patients to Standard Protocol patients. Feasibility was measured by adherence to study procedures. A cross-sectional survey design to assess both patient and provider experience with the program was conducted. Patient satisfaction was measured using the PSQ-18, and providers experience was evaluated with the Stanford Professional Fulfillment Index (PFI) and Burnout survey. Descriptive statistics summarized survey outcomes and demographics.

RESULTS

Participant Type	Total Visits	Protocol Adherence Deviations
RARE CAMELLIAS	18	2
Standard Protocol	78	28

Table 1: Protocol Adherence Results

Patient Satisfaction Questionnaire (PSQ-18) Results:
RARE CAMELLIAS

Average Overall Score	General Satisfaction	Technical Quality	Interpersonal Manner	Communication	Financial Aspects	TimeWith Doctor	Accessibility
4.65	4.33	4.75	4.83	5.00	4.17	4.50	4.75

Table 2: PSQ-18 results (n=3)

Provider Burnout and Fulfillment Scores:

RARE CAMELLIAS Visit Days			
Professional Fulfillment	Work Exhaustion	Interpersonal Disengagement	Overall Burnout
3.87	0.08	0.04	0.06
RARE CAMELLIAS Non-Visit Days			
Professional Fulfillment	Work Exhaustion	Interpersonal Disengagement	Overall Burnout
3.68	0.30	0.09	0.19

Table 3: PFI results on RARE CAMELLIAS visit days (n=9) and non-visit days (n=21)

Characteristic	Category	RARE CAMELLIAS Participants (n=5)	Non-RARE CAMELLIAS Participants (n=19)
Age at Diagnosis			
	30-44	0	3
	45-59	3	6
	60-74	2	10
Race			
	White	0	10
	African American	4	6
	Asian	0	1
	Other	1	2
Ethnicity			
	Hispanic/Latino	1	2
	Not Hispanic/Latino	4	15
	Other	0	2
Language			
	English	5	18
	Spanish	0	1
BMI			
	18.5-24.9	1	2
	25-29.9	0	3
	30-34.9	1	5
	35-39.9	1	3
	40+	2	6
Insurance Type			
	Private	0	6
	Medicare	2	8
	Medicaid	3	5
Average Roundtrip Distance Traveled (Miles)			
	Community Health Center	31.2	-
	University Hospital	280.4	55.8
Roundtrip Travel Burden Relieved (Miles)		249.2	-

Graph 1: Demographics of Clinical Trial Participants (n=24)

CONCLUSION

The preliminary results of the RARE CAMELLIAS program indicate feasibility as well as high patient satisfaction and enhanced provider experience. Compared to the Standard Protocol cohort, the RARE CAMELLIAS cohort demonstrated higher retention, fewer protocol deviations (89% vs 64%) and high patient ratings across multiple dimensions of care. Provider experience reported higher professional fulfillment and lower indicators of burnout on days which they saw RARE CAMELLIAS patients versus the days they did not. This suggests that benefits of the RARE CAMELLIAS model extend to both patients and staff. Collectively these outcomes display the potential of the RARE CAMELLIAS model in reducing logistical barriers to improve trial adherence, promoting equity in access to high-quality cancer care for underserved rural populations.

RECOMMENDATIONS

The initial success of RARE CAMELLIAS indicates a potential for hybrid models to address long-standing disparities related to cancer clinical trial participation. Expanding clinical trial access not only improves equity but also enhances overall standard of care practices, ultimately creating better outcomes for more patients. In Louisiana where the cancer incidence is 11.3% higher than the national average and roughly one-third of its population resides in rural areas, steps must be taken to bridge the gap between patient and specialist to allow for more equitable clinical trial access.

There are several limitations that must be considered when interpreting these findings. The primary limitation being the sample size, as only one clinical trial to date has been conducted using the RARE CAMELLIAS protocol, restricting its statistical power. Additionally, the single-site nature of implementation leads to the possibility of logistical, technological and cultural variation among rural communities that could diminish the effectiveness of the RARE CAMELLIAS protocol.

Leveraging the RARE CAMELLIAS infrastructure to support a broader range of clinical trials across additional rural parishes could yield valuable insights in the adaptability of its protocol. Continued observance of protocol adherence as well as patient and provider satisfaction will be essential in identifying regional barriers and refining implementation strategies. These efforts would ultimately support a more accessible and representative clinical trial landscape for those in rural Louisiana and beyond.

ACKNOWLEDGEMENTS

The Robert A. Winn Clinical Investigator Pathway Program (Winn CIPP)

LSUHSC, New Orleans, LA

Amelia Jernigan MD, Lucio Miele MD

Bristol Myers Squibb

References:
1. Tang, W. Z., Cai, Q. Y., Huang, K. J., Xu, W. Z., Li, J. Z., Pan, Y. R., Xu, H. Y., Zhao, Y. F., Sheng, T. H., Li, Z. M., Liu, T. H., & Li, Y. B. (2025). The global burden of polycystic ovary syndrome, endometriosis, uterine fibroids, cervical cancer, uterine cancer, and ovarian cancer from 1990 to 2021. BMC Public Health, 25(1), 1774. https://doi.org/10.1186/s12889-025-22881-3
2. National Cancer Institute. (2024). Cancer statistics. https://www.cancer.gov/about-cancer/understanding/statistics
3. Louisiana Department of Health. (n.d.). Rural parish map. https://ldh.la.gov/assets/docs/BayouHealth/DentalRfp12182012/Appendices/AppendixBB-RuralParishMap.pdf
4. America's Health Rankings. (n.d.). Explore rural population in Louisiana. https://www.americashealthrankings.org/explore/measures/pct_rural_b/LA
5. Reade, C., & Elit, L. (2012). Trends in gynecologic cancer care in North America. Obstetrics and Gynecology Clinics of North America, 39(2), 107-129. https://doi.org/10.1016/j.ogc.2012.02.003
6. Rural Health Information Hub. (n.d.). Rural health for Louisiana introduction. https://www.ruralhealthinfo.org/states/louisiana
7. National Rural Health Association. (2025). About rural health care. https://www.ruralhealth.us/about-us/about-rural-health-care
8. Garcia, M. C. (n.d.). Potentially excess deaths from the five leading causes, United States, 2010-2017. Retrieved August 6, 2025, from https://public.tableau.com/app/profile/macarena.garcia/viz/potentialty_excess_deaths_2010_2017/excessdeathsstoryboard
9. Jager, W. (2023). The importance of clinical trials in advancing medical research. Annals of Clinical Trials and Vaccines Research, 13(3), 93-98. https://www.openaccessjournals.com/abstract/the-importance-of-clinical-trials-in-advancing-medical-research-16485.html
10. Lee, Y. J., Lee, J. Y., Nam, E. J., Kim, S. W., Kim, S., & Kim, Y. T. (2025). Impact of clinical trial participation on the survival of patients with newly diagnosed advanced ovarian cancer. Frontiers in Oncology, 15. https://doi.org/10.3389/fonc.2025.1591000
11. Marshall, G. N., & Hays, R. D. (1994). The Patient Satisfaction Questionnaire Short Form (PSQ-18). RAND Corporation. https://www.rand.org/pubs/papers/P7865.html
12. Trockel, M., Bohman, B., Lesure, E., et al. (2018). A brief instrument to assess both burnout and professional fulfillment in physicians: Reliability and validity, including correlation with self-reported medical errors, in a sample of resident and practicing physicians. Academic Psychiatry, 42(1), 11-24. https://doi.org/10.1007/s40596-017-0849-3
13. U.S. Department of Agriculture. (2025). Rural-urban commuting area codes. https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes
14. Unger, J. M., McAneny, B. L., & Osarogiagbon, R. U. (2025). Cancer in rural America: Improving access to clinical trials and quality of oncologic care. CA: A Cancer Journal for Clinicians, 75(4), 341-361. https://doi.org/10.3322/caac.70006
15. Unger, J. M., Vaidya, R., Hershman, D. L., Minasian, L. M., & Fleury, M. E. (2019). Systematic review and meta-analysis of the magnitude of structural, clinical, and physician and patient barriers to cancer clinical trial participation. JNCI: Journal of the National Cancer Institute, 111(3), 245-255. https://doi.org/10.1093/jnci/djy221
16. Unger, J. M., Moseley, A., Symington, B., Chavez-MacGregor, M., Ramsey, S. D., & Hershman, D. L. (2018). Geographic distribution and survival outcomes for rural patients with cancer treated in clinical trials. JAMA Network Open, 1(4), e181235. https://doi.org/10.1001/jamanetworkopen.2018.1235
17. Collins, Y., et al. (2014). Gynecologic cancer disparities: A report from the Health Disparities Taskforce of the Society of Gynecologic Oncology. Gynecologic Oncology, 133(2), 353-361. https://doi.org/10.1016/j.ygyno.2014.02.026
18. Shalowitz, D. I., Vinograd, A. M., & Giuntoli, R. L. (2015). Geographic access to gynecologic cancer care in the United States. Gynecologic Oncology, 138(1), 115-120. https://doi.org/10.1016/j.ygyno.2015.04.025
19. Boland, M. R., Tubridy, E., Solorzano, S. S., Simpkins, F., Smith, A. J. B., & Ko, E. M. (2024). Geographic disparities in gynecologic oncology clinical trial availability in the US. JAMA Network Open, 7(11), e2447635. https://doi.org/10.1001/jamanetworkopen.2024.47635
20. Louisiana Department of Health. (2025). Cervical cancer. https://ldh.la.gov/office-of-public-health/cervical-cancer
21. Centers for Disease Control and Prevention. (2025, February 3). Gynecologic cancers basics. https://www.cdc.gov/gynecologic-cancer/about/index.html
22. Ricci, S., Tergas, A. I., Long Roche, K., et al. (2017). Geographic disparities in the distribution of the U.S. gynecologic oncology workforce: A Society of Gynecologic Oncology study. Gynecologic Oncology Reports, 22, 100-104. https://doi.org/10.1016/j.gore.2017.11.006