

Appendix A: Sample Application

Aim of the project

In view of COVID-19, this project will address healthcare disparities in the South Asian (SA) community and build a community understanding of clinical research. It will help bridge the gap in healthcare literacy by educating the community with information from reliable sources:

1. To form a community advisory group to help develop a clinical research education program for South Asians.

2. To develop a culturally tailored brochure for encouraging participation of SAs in clinical research trials through translation of the information about clinical research with input from the SA community.

3. To seek input from the SA community about the feasibility and acceptability of education of clinical research trials in a temple setting.

Background

Sai Datta Peetham is a non-profit organization in South Plainfield, NJ and serves the SA population, mostly Indian American community. SDP is proposing a pilot project to address the need for clinical research education in the SA community during the COVID-19 pandemic, and people of Indian origin are 80% of the South Asians (Volgman et al., 2018). Collaborating with South Asian Total health Initiative (SATHI) at Rutgers University, SDP leadership, and volunteers will outreach using the clinical research trial resources translated into Telugu, a major language spoken.

Out of the New Jersey's nine million residents, there are 384,000 Indian Americans who are part of the fastest growing minority, including the SDP community comprising Telugu-speaking South Indians in the Edison and surrounding towns. This immigrant community has low healthcare literacy, limited English language proficiency, and the need for healthcare resources (Bailey, Sattar, & Akhtar, 2018). By providing a culturally competent clinical research education, we plan to affect this community's healthcare. This project will remove the communication barriers through clinical research education in Telugu, the primary heritage language of this population.

The pilot project will address health equity because of the language barrier and build modes of research through translation to bring an understanding of clinical and translation research of COVID-19. The need and the process of research to bring new treatment to the community is becoming so important for all persons to understand and take part in the research. The South Asian population is a large subset of the South Asian Americans in New Jersey, to show how to create the gap. As South Asian Americans ourselves, we have experienced examples of communication gaps between health care professionals and patients.

Sai Datta Peetham (SDP) Community Center has shown its experience in medical community partnership as it has taken part with SATHI at Rutgers University changing the Diabetes Prevention Program (DPP) curriculum developed by CDC. The New Jersey Alliance funded this project for Clinical and Translational Science (NJACTS). SDP participants have reviewed the curriculum, discussing the modules in great detail at advisory group meetings. SDP held meetings to seek feedback, generate

ideas, and suggestions from the community about the South Asian Diabetes Prevention Program.

SDP also took part in the Diabetes Clinic conducted by Shailja Mathur M.S., M. Ed., RDN, Sr. Program Coordinator, Department of Family and Community Health Sciences (FCHS); SATHI at Rutgers University; Coordinator, Rutgers Cooperative Extension. Also promoted the diabetes series and Diabetes Forum for Indian women in the community.

Organizations, Staff and Rutgers/IFH faculty Involved

- Raghu S. Sankaramanchi, Sai Datta Peetham Community Center, South Plainfield, NJ, (732) 809-1200.
- Sunanda Gaur, MD, Professor of Pediatrics, Director Robert Wood Johnson AIDS Program, Director Clinical Research Center, Director South Asian Total Health Initiative, Rutgers RWJMS, New Brunswick NJ.
- Usha Ramachandran, MD, Associate Professor of Pediatrics, Associate Director, South Asian Total Health Initiative, Rutgers RWJMS, New Brunswick, NJ, Medical Director, Reach Out and Read New Jersey.
- Anupam Ohri, MD, Associate Professor, Department of Medicine, Division of Endocrinology, Rutgers-RWJMS, New Brunswick NJ.

Letters of Recommendation

Dr. Sunanda Gaur, Dr. Usha Ramachandran, and Dr. Ohri, who have experience in working with SDP and have knowledge of the organizational capacity of prior history in the DPP Curriculum development project, provided letters of recommendation.

Program Implementation

AS clinical research trials information is currently not available in SA languages, this project can support Rutgers University's website serving NJ's diverse population with the translated information in Telugu: <https://www.rutgers.edu/news/rutgers-translates-covid-19-information-new-jerseys-diverse-population>.

Project Plans

Advisory group (AG): This project seeks to empower the SA community to enhance the decision-making power by providing information about clinical research trials and facilitate learning in the community. We will create an advisory group to include:

- a. SDP Translation Team, Rutgers/IFH Faculty, and Coordinator
- b. Temple management
- d. Members of the SA community

The advisory group will meet 4 times during the project. The aim of the first two meetings is to understand the subject matter, the problem defining, and exploring community resources, seeking solutions, seeking agreement from community members. We will devote subsequent meetings to exploring what modifications we need to adapt the translated brochure to be specific, relevant, and culturally appropriate for SAs. We will change the brochure with the feedback from the advisory committee members. Once completed, further input regarding the feasibility and acceptability of the clinical research program from a larger group of temple staff and community members. The desired outcomes will include:

- Completion of 4 advisory group meetings
- Presence of at least 2 members from the SA community at the advisory committee meeting.
- Conduct two larger community meetings at the temple to get further input.

Project Timeline by month

Time Period	Activities
Quarter 1	Identify team of translators and Introduction of the translated material
Quarter 2	Creation of project advisory group in SDP
Quarter 3	Discuss Clinical Research in the community
Quarter 4	Change resource material and more education

Proposed Budget

Description	Est. Time	Cost
Resource Material Translation & Review	3months	\$2,000
Outreach to understand perceptions about Clinical Research	3 months	
Community Education about Clinical Research	3 months	
Outreach to seek feedback about Clinical Research Education	3 months	
Food, Facilities, and Communication		\$2,500
Miscellaneous		\$500
Total Budget		\$5,000

Future Applications and impact

This project will improve the healthcare equity, especially during and post COVID-19 pandemic through education to reduce communication barriers. The outcome will lead to better understanding of clinical and translational research, improve research participation, better understanding of vaccine research and potentially improve vaccine acceptance in the community. This project could serve as a model for similar projects and partnerships with other South Asian community groups.

At the project completion, we will develop a framework for a SA clinical research trials program. We will continue the collaboration with the Rutgers RWJ Medical School by continuing to seek their input into evaluation of the program.

References

- Bailey C, Sattar Z, Akhtar P. (July 3, 2018). Older south Asian women sharing their perceptions of health and social care services and support: A participatory inquiry. *Health Sci Rep.*,1(8): e55. doi:10.1002/hsr2.55.
- Jersey Promise- A Report on the State of Asian Americans in New Jersey.
<http://jerseypromise.org/wpcontent/uploads/2019/05/Jersey-Promise-Report-Final-5.5.2019.pdf>.
- SAALT (South Asians Learning Together). (2019). A demographic snapshot of South Asians in the United States. <http://saalt.org/wp-content/uploads/2019/04/SAALT-Demographic-Snapshot-2019.pdf>.
- Volgman AS, Palaniappan L.S., Aggarwal N.T., et al. (2018). Atherosclerotic Cardiovascular Disease in South Asians in the United States: Epidemiology, Risk Factors, and Treatments: A Scientific Statement from the American Heart Association. *Circulation*, 138 (1). doi:10.1161/cir.0000000000000580.