

Sample ARCC Letters of Intent (LOI)

The attached document is a sample of a successful LOIs submitted by a community-academic teams to the **ARCC Seed Grant Program**. It may be helpful to look at these examples but please keep in mind to carefully craft a LOI to meet the specific requirements of the funding opportunity being pursued.

For additional information on the ARCC Seed Grant Program:

<http://www.nucats.northwestern.edu/funding/seed-grants/arcc-seed-grants/index.html>

Sample ARCC CBPR Partnership Building Grant LOI

This document serves as our letter of intent to apply for an ARCC Partnership Building grant that will explore the feasibility of a community-academic partnership to increase HPV vaccination in the African American community.

CO-PIs

ACADEMIC : Name, Title, Department/Institution, Address, Email, Phone

COMMUNITY: Name, Title, Organization, Address, Email, Phone

The human papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the U.S. and is associated with the vast majority of cases of cervical cancer. The rate of cervical cancer among Black women is 50% higher than that of white women and Black women have the highest cervical cancer death rate of any group of women in the U.S. The HPV vaccination helps prevent cervical cancer, yet Blacks have the lowest HPV vaccination rate of any group.

CBO would like to partner with Dr. W to build a coalition of groups interested in defining and overcoming barriers to HPV immunization in Chicago, identify interventions, develop possible pilot activities using some of these approaches, and apply for an ARCC implementation grant. SWIO is uniquely positioned to serve as a community convener and to conduct CBPR. Dr. P, an internist at the University of X, organized CBO 10 years ago to empower African American women to become health educators in their own communities and advocate for policy changes. Although the organization started with a focus on breast cancer, it has expanded to include all aspects of women's health.

CBO's activities are based on the community engagement/CBPR approach. Dr. P has extensive CBPR experience and has published journal articles and presented at CPH. Dr. P will serve in an advisory capacity, as well as facilitate workshops on community-academic partnerships, CBPR, etc. Ms. R, the CBO Co- Program Director, is an extremely visible, respected and trusted community gatekeeper on the south side of Chicago; she has extensive experience in training community health workers, and is working on an MPH degree at DePaul University. Ms. R will serve as the Co-PI for this partnership. CBO Board of Directors member and Co-Program Director, Ms. C, has extensive CBPR knowledge and experience, as well as knowledge in building community-academic partnerships. Ms. C will serve in an advisory capacity, will attend each monthly meeting and will co-facilitate trainings such as Human Subjects Protection and CBPR 101. Dr. W also has a long history of community engagement and is an expert on infectious diseases, specifically HPV. She will serve as the academic Co-PI for this partnership and will facilitate workshops on infectious diseases, HPV, vaccinations, traditional research, etc. Community partners will serve as advisors, community experts and ultimately community researchers.

One of the barriers to immunization, including HPV immunization, in the African American community is the long-standing distrust of injections, medicine, and researchers. Dr. W, CBO leadership, and CBO members agree that this dynamic clearly calls for a CBPR approach. In this project, researchers and community members are equal partners in creating a research coalition to identify and remove barriers to immunization.

Currently, we have three community partners that have a firm commitment to this effort: The ABC Community Family Life Center, a community organization in Washington Park that has a strong afterschool program and parent council, as well as a key partnership with XYZ High School (located in Englewood; school also has a strong parent council); Church, a young, 2000 member congregation in Chicago's Woodlawn area; and Network in the Roseland/Fernwood Community area that serves thousands of households on the far south side. Other potential partners identified are: Chicago Public Schools, particularly schools with Public Health tracks such as New Millennium High School; the Chicago LMN Program, a support group for grandparents thrust into the role of primary caregiver for school-aged children, QRS Minister's Coalition, First Ladies, and Girl Scouts.

The goals of this proposed partnership are to:

1. identify and meet with potential community partners for a broad immunization effort
2. educate community partners about HPV in African Americans and the HPV vaccine
3. learn what they think the barriers to HPV immunization are
4. brainstorm about community-based research projects which would both test novel ways to overcome barriers to immunization and result in the immunization of adolescents

5. Identify potential funding sources for implementation

Longer-term goals of this 12-month project are to translate the ideas and interventions we gather into action and to apply for a 2013 ARCC implementation grant to remove barriers and promote immunization.

Prefunding activities will include CBO members and Dr. W participating in a CBPR 101 workshop, completing internet modules on CBPR from the Community-Campus Partnerships for Health website, and obtaining Human Subjects Protection Training and IRB Certification. CBO members and Dr. W will brainstorm to identify potential partners, and conduct preliminary inquiries about their interest.

Upon funding, the council will convene monthly 2.5 hour meetings. Most meetings will split the time between partnership and capacity building activities. The project timeline is as follows:

- Month One: develop and send formal letters to community partners announcing funding, establishing meeting times, locations (alternating partner locations).
- Month Two: Informal meet and greet with community partners and Dr. W, become familiar with each organization and identify additional partners that should be involved.
- Month Three: Begin developing roles and responsibilities. Dr. W will present an in depth overview of HPV, the HPV vaccine, myths, and barriers encountered when attempting to vaccinate youth.
- Month Four: Develop conflict resolution procedures. Workshop on Traditional Research
- Month Five: Council will discuss finances; project costs, funding allocation etc. Workshop on CBPR 101
- Month Six: Dr. W will facilitate discussion on community-based research projects which would both test novel ways to overcome barriers to immunization and result in the immunization of adolescents
- Months Seven: Council will begin developing MOUs. Workshop on CBPR Partnerships.
- Month Eight: Develop shared decision making procedure. Workshop on developing research questions.
- Month Nine: Ms. C and NU IRB staff will facilitate Human Subject Protection and IRB Certification Training
- Month Ten: Summarize potential activities for presentation to and review by partners; decide on the feasibility of going forward and if so begin developing project proposal and identifying funding sources.
- Month Eleven: Finalize development of ARCC implementation project proposal in anticipation of ARCC 2013 seed grant round.
- Month Twelve: Develop one pager debriefing partnership outcomes and next steps. Disseminate one pager to community partners via community papers, partner organization newsletters, etc. Develop abstracts for submission to local and national conferences.

Based on the activities described above, we anticipate applying for a partnership building grant of approximately \$9750.

Sample ARCC CBPR Implementation Grant LOI

The Coalition, represented by Ms. D, and Dr. M, a member of the Lurie Children Hospital (LMH) palliative care team and palliative care researcher, write to express our interest in applying for a Community Based Participatory Research Implementation Grant. Our proposed project will evaluate our adapted needs assessment tool for parents of children with life-limiting illnesses. This work will strengthen our partnership and provide a foundation for future community based participatory research to improve the care of dying children and their families in the community/home setting of Chicagoland and the greater Illinois region.

The Coalition/LCH partnership

The Coalition is a nonprofit, 501 (c)(3), Illinois organization interested in improving access to quality, community-based, pediatric palliative care services. GIPPCC coordinates collaborative educational, advocacy and clinical improvement projects for members to further the GIPPCC mission: To ensure that all Illinois children with life-limiting illnesses and their families have access to the highest quality palliative care programs. Members include any agency or individual who shares the Coalition's vision. Non-profit, community-based palliative care programs make up about 75% of Coalition's total membership. See www.xx.org for further information. Representatives from the LCH palliative care team, including Dr. M, have substantially contributed to Coalition's achievements through the provision of expert advice, resources and time.

Three years ago, Dr. M obtained a grant to support the implementation of a pediatric family satisfaction survey developed by the coalition's interdisciplinary team. With the goal of using the survey to measure quality and identify areas needing improvement, Dr. M and Coalition worked collaboratively to implement the pediatric-focused survey at three coalition member sites. The surveys are distributed and collected by individual organizations; the information is then anonymously shared with Coalition for regional collation. This provides a larger body of data regarding family satisfaction, as well as an opportunity for organizational benchmarking. Through this project, we have developed a framework for coordinated survey distribution and collection, and a potential research infrastructure among different community-based organizations who share a common vision.

However, we have encountered barriers to engaging in collaborative research. None of the community-based palliative care organizations have an institutional review board (IRB). And no mechanisms or support exist to collaboratively develop and implement research across the different community-based Coalition member organizations, most of which support pediatric palliative programming through philanthropic grants. We are applying for this Community Based Participatory Research Implementation Grant to conduct needed research in community-based pediatric palliative care and to expand into a research capable partnership that will benefit families in Chicagoland communities.

The Need

Almost 25,000 children in the United States die outside the hospital setting. Access to home-based palliative care allows families to spend their child's last days surrounded by the comforts of home, while minimizing health care costs. Providing quality interdisciplinary palliative care in the community setting imposes unique challenges. The palliative care literature shows a gap in what dying children and families want or need and the care they receive. Patient-centered care requires clinicians to identify existing needs. Yet, no practice-derived, theory based, empirically validated tool exists to assist pediatric palliative care teams with identifying family needs. Such a tool would help community-based families communicate needs to multidisciplinary palliative care teams who could then individually tailor care and resources, thus closing the gap between needs and services received.

Research Aims/Project Description

We developed the Parent/Child Needs (PC Needs) Tool as an adaption of the validated adult tool, Needs at the End-of-Life Screening Tool (NEST). We created PC Needs with input from Dr. M, Dr. D (psychology professor at University of Buffalo and Director of Research at the Center for Hospice & Palliative Care in Buffalo), Coalition members, pediatric palliative care experts, and bereaved parents. The goal of this project is to use a community based partnership approach to evaluate the reliability and validity of the PC Needs Tool and to assess the feasibility of using this tool in the community setting to improve care. Through this project we will further develop the necessary research infrastructure among Coalition, Coalition member organizations, families in the community, and LCH to provide a solid foundation for future research—all for the benefit of families caring for dying children at home. The specific aims of our research partnership are as follows:

1. Develop a research capable partnership to implement this and future research projects

- a) Establish a research planning and implementation (RPI) group. This group will include representatives from Coalition, interested Coalition member organizations, parents of children who have received/are receiving palliative services and Dr. M. The group will concentrate on furthering the functionality of our existing partnership, including drafting a memorandum of understanding to guide collaborative work and identifying and eradicating potential roadblocks to a successful research partnership. The group will also guide research design, providing insight into optimizing data collection and dissemination of research results to involved organizations, individuals and parents.
- b) Obtain IRB oversight for Coalition member organizations interested in conducting research. Dr. M will work with the Coalition member ABC Hospice and Palliative Care (ABC), a Chicago-based hospice program that has respectfully cared for

individuals at the end of life since 1978, and the LCH IRB to establish a contractual agreement allowing the LCH IRB to oversee certain research activities at Horizon in conjunction with LCH faculty. We will start with ABC because they have a large pediatric palliative care population (approximately 20-30 patients at any time) and because they already have a Federalwide assurance number, the first step in this process. Using our experience with ABC as a model we will then branch out to other interested Coalition members, likely including two other hospice organizations during the course of the two-year period.

2. Determine the reliability and validity of the PC Needs Tool

- a) Collect data on parent needs of children with life-limiting illnesses using our PC Needs Tool and one-on-one parent interviews. We will disseminate a written questionnaire using the infrastructure established for collecting the Coalition satisfaction survey with refinements as defined by the RPI group. Preliminary research discussions revealed a need to use a paper survey in conjunction with the satisfaction tool, because many families do not have computer access. The RPI group will readdress this issue prior to and during data collection. Dr. M's research coordinator, a sociology PhD candidate, will accompany nurses on home visits to conduct semi-structured recorded interviews with parents using an interview guide asking about needs. Data collection will start with the families served by ABC and extend to other member organizations as IRB oversight is obtained. Based on our experience with the satisfaction survey (84 surveys collected from 3 organizations over 15 months) we anticipate collecting 30 surveys from families over a one year period, assuming we eventually involve at least 2 member organizations.
- b) Analyze Data: We will input data into a password-protected electronic database housed at LCH. We will determine reliability via examination of item-total correlations and overall reliability with Cronbach's Coefficient Alpha. We will examine construct validity through comparison of our tool with three constructs: socioeconomic status, quality of life, and social support (items measuring these constructs are included in the questionnaire) and by comparing survey results with interview results. We anticipate interviewing 10 – 15 parents. We estimate needing 26 returned surveys based on our expectation of the minimum correlation needed (0.50 with statistical power of 0.80) to demonstrate construct validity between the total PC Needs score with the quality of life and social support scales.

3. Refine PC Needs Tool based on our findings

Reconvene the RPI group and Dr. D to examine and discuss the collected data and consider alterations needed to the PC Needs tool to improve functionality or validity.

4. Plan for future research/funding

The RPI group will develop strategies for integrating the PC Needs Tool into clinical care in order to inform healthcare teams about families' unmet needs. We will develop an action plan to address those needs and test the impact of such interventions. This will help achieve a Coalition goal of assessing and addressing the needs of seriously ill children and families in rural areas and resource poor urban areas of Illinois. We will seek additional funding for such work from organizations such as the National Institutes of Health, the Agency for Healthcare Research and Quality, or from foundations such as the National Palliative Care Research Center.

Study Timeline and Budget

We will utilize the first six months to complete aim 1 (yet, obtaining IRB oversight for multiple members will likely extend for 12 months), months 6 – 18 for data collection, and months 18 – 24 for data analysis, tool refinement, manuscript preparation and planning for future research. We request \$25,000 for this project to support efforts from Coalition personnel, Coalition member personnel, and LCH personnel engaged in this research and the cost of transcribing interview data, statistical support and other research related costs.

CBPR Training

Both Co-Principle Investigators involved in this project have participated in CBPR education activities through ARCC. Dr. M attended the workshop entitled, Practical Guidance for Authors Writing about CBPR in April 2011. Ms. D attended the research question and design seminar, by MaryAnn Mason and Lucy Gomez-Feliciano, in November 2011. Additionally, Ms. D and Dr. M plan to attend future ARCC programming, including the Collaborative Data Analysis workshop on March 7, 2012, to gain further education in community based participatory research.

Co-Principle Investigators

Community Co-Principle Investigator
Name/Title
Organization/Institution
Address/ Phone number
Email

Academic Co-Principle Investigator
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