Seed Grant Program Examples of Successful Applications

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<u>Please note</u>: The seed application requirements, criteria, funding amount, etc. differ between rounds. Keep this in mind when reviewing these applications.

Sample ARCC 2023 Community Research Capacity-Building Seed Grant Application

Title: Increasing the capacity of Community Health Workers to become leaders in community-engaged research through development of orientation and training modules

C1. Summary of proposed capacity-building (Up to 150 words): This should be written in lay language and able to stand alone. If funded, it will be used in grant award announcements.Please include: any communities of focus and/or geographic focus; and the main aims of your application.

The HAP (Hospice and Palliative) Foundation seeks to increase the community-engaged research capacity of its Community Health Worker (CHW) team through development of culturally informed, discipline-specific orientation modules that focus on the core principles of this research modality. A CHW is a frontline public health worker who is a trusted member of the community; this relationship enables the CHW to be a liaison between community members and health/social services, thereby improving the quality and cultural competence of health service delivery. The HAP CHW team seeks to empower communities through education, relationship building and connectivity but also by facilitating community-led research that will drive solutions to community challenges. Through CHW training, the HAP Foundation will increase organizational capacity to conduct community-enhancing research in the space of serious illness and grief, ultimately seeking to build community trust in the research paradigm and increase community involvement in development, implementation and dissemination of critical community-driven research.

C2. Why Your Organization or Community Wants to Build Research Capacity (Up to 150 words):Describe why your organization or community is interested in focusing on developing orstrengthening research capacity. Include how the focus is of importance to community members(people with lived experience, beyond community organization leaders) and processes yourorganization has undertaken to identify this focus.

Palliative and hospice care increase quality of life, alleviate symptom burden, decrease emergency room visits and reduce overall healthcare spending. Despite these benefits, these services are not consistently utilized for serious illness care; in fact, tremendous disparity exists in utilization of hospice and palliative services. Hospice utilization shows that of all Medicare decedents, 14% fewer members of Black communities and 11% fewer members of Latinix communities utilize hospice, as compared to their white counterparts. A recent research partnership between NORC at University of Chicago and HAP's CHW team has ignited an organizational passion regarding the power and influence of research. The NORC partnership sought to better understand knowledge, attitudes and behaviors around hospice and palliative care in Black communities in Chicago. This research work has created an organizational urgency to investigate disparate use of hospice services more robustly. Inspired by the consequential weight of the preliminary findings in the NORC project, HAP has a renewed commitment to sculpt our work through data reflection and cultural competency, and the CHW team is enthusiastically embracing research as a powerful tool to drive this vision.

C3. Describe your planned goals and strategies for the grant (Up to 350 words): What will this grant prepare your organization(s) or community to do next? Possible activities are described in the RFA. Include if there are any plans to engage community members (people with lived experience) beyond community organization leaders.

HAP seeks, in consultation with an expert in the community-engaged research space, to develop research orientation modules for our CHW team. The orientation modules will seek to increase comprehension of the community-engaged model of research, acclimate to research sensitivities

around serious illness/grief, strengthen CHW data comprehension and application, and contextualize the work through the lens of historical mistrust and missteps in the research space. This work will be done in consultation with a respected, Chicago-based colleague, [redacted], Community Epidemiologist of [redacted]. [redacted] has over 30 years' experience as a public health practitioner and more than 15 years engaged as a Community Epidemiologist researcher with [redacted]. Her deliverables will be to work with the team to guide and inform on content and context subject matter pertaining to CHW's data competencies in research interpretation and application. Additionally, [redacted] is deeply involved and appreciative of the CHW work in our region, leading to a unique understanding and respect for the CHW role that will facilitate cooperative, adult learning. While we have general scaffolding in mind for development of orientation modules, we do intend to commit time for dialogue to identify the optimal structure for the modules. Ultimately, we envision three short modules that (1) review the framework of community engaged research, (2) contextualize the focus on community-led research through the lens of the deep history of research malevolence, and (3) strengthen data comprehension to ensure robust dissemination within the community. The CHW position is inherently designed to increase trust and connections in the community between individuals and healthcare systems. To that end, [redacted] feels it is critical to contextualize the CHW work in research through the lens of historical racism, mistrust and trauma. Without this awareness and sensitivity training, our intent to engage the community in empowering and system-modifying research risks doing more harm than good. The ultimate intent of this project is to build the research capacity of the CHW team in preparation for future academic partnerships. We anticipate that CHWs, as members of the community they serve, will act as vital contributors within research leadership teams. Our education modules will also seek to ensure robust awareness regarding inclusion of community members in leadership positions. We anticipate that this work could be transferable to other CHW program models to support increased capacity of community-engaged research for CHWs as a healthcare discipline.

[redacted], we understand that data-informed decision-making benefits everyone. The [redacted] is committed to conducting its own research and supporting ongoing field research around the impact of palliative and hospice care on patients and their families. Findings are used to inform our education and advocacy

Budget Narrative

Personnel $1000 is requested from ARCC to support the time of two [redacted] staff members dedicated to this project: [redacted], CHW, Community Education Associate and Research Liaison and [redacted] Executive Director of Program Evaluation and Research.

$500 will go toward the salary time of [redacted](30 hours) in developing CHW curriculum for community engaged research; additional salary funding required for work on this project (around $1,000) will come from philanthropic funding from [redacted] that is designed to support the education and community-engaged research work of [redacted] Foundation's CHWs

$500 will go towards the salary time of [redacted] (30 hours); additional salary funding required for work on this project (around $1500) will be directed by [redacted] general budget towards the time spent by this staff member.

Consultant Fees

$1500 is requested from ARCC to support a stipend for a consultant on this project.

$1500 to support 20-25 total hours of time from a consultant ([redacted]) with experience in community-engaged research, historical malevolence in the research space and data literacy, as well as experience working with community health workers.

The [redacted] will use line item budget contributions from our general budget to cover mileage and meetings; we anticipate a single in person meeting with continued work being completed over zoom.

Title: Building Capacity for the Healthy Southwest Coalition for Food Security

C1. Summary of proposed capacity-building (Up to 150 words): This should be written in lay language and able to stand alone. If funded, it will be used in grant award announcements.Please include: any communities of focus and/or geographic focus; and the main aims of your application.

The Southwest Organizing Project (SWOP) is a broad-based organization committed to collective action for the common good. The aim is to build an evidence-based actionable food security campaign based on both quantitative and qualitative community research. Southwest Chicago communities have 60.55 ±0.86% of residents (2016-2020) that are Hispanic/Latino. As we build the capacity to serve this community, our health equity team, Healthy Southwest, has identified food insecurity as one the primary key social determinants of health that impacts the wellness of these communities. Hispanic and Latino community members of Southwest Chicago have been historically marginalized, and by prioritizing a deeper understanding of the root causes of the food insecurity is paramount. Community-based participatory research (CBPR) will allow for a unique approach to organizing Southwest Chicago's thirteen neighborhoods, and creating seats at the table for community-driven solutions to reduce the disparities leading to high levels of food insecurity.

C2. Why Your Organization or Community Wants to Build Research Capacity (Up to 150 words):Describe why your organization or community is interested in focusing on developing or strengthening research capacity. Include how the focus is of importance to community members(people with lived experience, beyond community organization leaders) and processes your organization has undertaken to identify this focus.

SWOP formed in 1996 to challenge the history of structural racism on the southwest side of Chicago. Recognizing that the responsibility of eradicating structural racism lies with the full community and not just with people of color, SWOP leaders work to build relationships across differences and understand that large disparities exist especially in communities of color. SWOP does this through a community organizing strategy that creates spaces and opportunities for families to share stories and experiences that help them identify common interests and respect the traditions and cultures that differentiate us. SWOP's staff is 86% people of color and believes that those who are closest to the issues are also closest to the solutions. The infrastructure for food security in southwest Chicago is minimal at best; and in many neighborhoods, there is low food access and a high percentage of residents who are eligible for SNAP benefits, but are not enrolled is as high as 80%. By creating the infrastructure for an efficient and sustainable food network in southwest Chicago, this will be impactful for many community members that struggle with this basic need.

C3. Describe your planned goals and strategies for the grant (Up to 350 words): What will this grant prepare your organization(s) or community to do next? Possible activities are described in RFA. Include if there are any plans to engage community members (people with lived experience) beyond community organization leaders

The primary goal is to develop community-driven research to identify the social determinants of health & the root causes that directly impact the quality of life in southwest Chicago communities. Uniquely, we will be focusing on identifying solution-focused research questions to address root causes of health inequities including assessing environment and capacity of community members & organizations through 1-to-1 interviews to collect quantitative and qualitative research. Objectives include identifying leaders of community based organizations that work on improving food security for their communities. Through leaders & community members in southwest Chicago, the goal is to provide compensation (grocery store gift cards) for interview participants to incentivize a diverse array of community members that are seeking food assistance of varying backgrounds to help us build strategy & capacity for actionable steps for our upcoming food security campaign.

Title: ***Development of Community Advisory Board in Chicago's South Side Maternal Health Desert***

C1. Summary of proposed capacity-building (Up to 150 words): This should be written in lay language and able to stand alone. If funded, it will be used in grant award announcements. Please include: any communities of focus and/or geographic focus; and the main aims of your application.

The South Side of Chicago is classified as a 'maternal health desert' due to lack of obstetrical services. Black birthing people on the South Side have the highest Maternal Mortality Rate in Illinois (3x that of white women in Illinois). Holistic Birth Collective's (HBC) Co-founder is the only Black, Certified Professional Midwife qualified to provide out-of-hospital midwifery care in the state of Illinois. Her work with South Side families and the work of HBC's other co-founder, a data activist on the South Side, led to a Community Birth Study in two South Side Hospital Regions. Additionally, HBC purchased a state-wide secondary data set of all perinatal discharge data for 2018-2021 to understand service utilization in relation to perinatal outcomes in Illinois. ARCC seed funds will support establishing a Community Advisory Group to ensure our proposed research aims, methodologies, approaches, and dissemination strategy align with communities that we Center.

C2. Why Your Organization or Community Wants to Build Research Capacity (Up to 150 words): Describe why your organization or community is interested in focusing on developing or strengthening research capacity. Include how the focus is of importance to community members (people with lived experience, beyond community organization leaders) and processes your organization has undertaken to identify this focus.

State funding for the Community Birth Survey and Focus Groups came quickly and unexpectedly from administrative advocacy work we were doing on behalf of Black birthing people in our community. We had only one year to gain approvals and complete data collection, which did not give us ample time to think through setting up a community advisory board.

With survey data collection complete and before we analyze the survey data and finalize the data request for the secondary data set, we have a minute to breathe. The formation of the Community Advisory Board is a critical next step in centering community voices and grounding the work in the communities in which we Work. We are also applying for the ARCC Partnership Development Grant with Dr. Kiarri Kershaw. Establishment of a Community Advisory Board will lay an important foundation for our partnership to move forward with confidence and community input/guidance.

C3. Describe your planned goals and strategies for the grant (Up to 350 words): What will this grant prepare your organization(s) or community to do next? Possible activities are described in the RFA. Include if there are any plans to engage community members (people with lived experience) beyond community organization leaders.

During 2022, HBC designed, gained ethical approval for, launched and completed data collection for our Community Birth Survey. We engaged with 66 community organizations and recruited 452 new parents in the study catchment area (Illinois Hospital Regions A-3 and A-4 on the South Side of Chicago) to fill the survey. Additionally, we held three focus groups with community birth workers and new parents in the catchment area.

Additionally, in 2022, HBC purchased a large dataset from the Division of Patient Safety & Quality at the Illinois Department of Public Health (IDPH). These patient-level data cover all hospital inpatient and outpatient discharges relating to pregnancy, abortion, childbirth, neonatal complications, and perinatal complications and will provide crucial insights into utilization and costs associated with reproductive health services statewide. We would like to explore the feasibility of reporting the secondary data from the same geographical area (South Side of Chicago) during overlapping time periods as our community birth survey and focus group data.

We request Capacity Building grant funds to establish a Community Advisory Group (CAG) to ensure the proposed research aims, methodologies, approaches, and dissemination strategy align with the communities in which we live and work. We plan a 5-7 member group recruited from the community birth

survey respondents, focus groups participants, and other reproductive health and justice grassroots organizations in our catchment area. Our overall goals are to present preliminary findings from the Community Birth Survey and collect feedback as to the direction of further analysis and dissemination on the survey data and the secondary data set.

Vision for Community Advisory Group:

• 5-7 members of the committee (odd number to ensure the group can come to consensus)
• Recruit from the community birth survey, focus groups, and other grassroots organization
• Initial Meeting (#1) - Establishing the purpose, relationship building, establishing group values, identifying the CAG's "why"
• Collective visioning session (#2) – Graphic illustrator (this will be a graphic of the "vision" that helps ground the group)
• Deep-dive into research meeting (#3) - Describe the data sources and offer research questions for the CAG consider
• Second deep-dive research meeting (#4)– Revisiting the discussion about the research questions and solidifying the questions that will be prioritized
• Meet every two-three months thereafter to provide updates about the analysis

ARCC Community Capacity-Building Seed Grant Budget Justification

• Funding will provide honorariums for CAG members, transportation vouchers, food, etc.
• Initial Meeting (#1) - Establishing the purpose, relationship building, establishing group values, identifying the CAG's "why"
• Collective visioning session (#2) – Graphic illustrator (this will be a graphic of the "vision" that helps ground the group)
• Deep-dive into research meeting (#3) - Describe the data sources and offer research questions for the CAG consider
• Second deep-dive research meeting (#4)– Revisiting the discussion about the research questions and solidifying the questions that will be prioritized
• Meet every two-three months thereafter to provide updates about the analysis
• Community Lead and Community Consultant time will be covered by [redacted] general operating funds
• Meeting venue costs will be covered by HBC general operating fund

ARCC SEED GRANT APPLICATION

Building Capacity for a Community Based Research Partnership to Optimize Physical Activity in Lung Cancer Survivors

Application type:

Research Partnership Development Award

Contact Information:

Community Co-Principal Investigator:

Academic Co-Principal Investigator:
Dr. , MD, PhD
Attending Physician, Clinician Scientist
Shirley Ryan Abilitylab (formerly Rehabilitation Institute of Chicago)
Assistant Professor, Physical Medicine and Rehabilitation, Northwestern Feinberg School of Medicine

Co-Investigator:
MD, Attending Physician
Robert H. Lurie Comprehensive Cancer Center
Associate Professor, Medicine-Hematology and Oncology, Northwestern Feinberg School of Medicine

Co-Investigators/Consultants:
- , MD (PGY-3), Dept. of Physical Medicine and Rehabilitation, McGaw Medical Center, Northwestern University
- , MD (PGY-3), Dept. of Physical Medicine and Rehabilitation, McGaw Medical Center Northwestern University
- MD (PGY-2), Dept. of Physical Medicine and Rehabilitation, McGaw Medical Center Northwestern University
- MA, LCPC, Program Director, Gilda's Club Chicago
- , PhD, Director of Supportive Oncology, Robert H. Lurie Comprehensive Cancer Center

Building Capacity for a Research Partnership to Optimize Physical Activity in Lung Cancer Survivors

SUMMARY

Lung cancer is the most common cause of cancer related death in the United States with over 200,000 new cases diagnosed annually.[1] The disease is commonly associated with smoking. and people afflicted present with numerous debilitating symptoms such as difficulty breathing, cough, weight loss, insomnia, fatigue, pain and on occasion mood disorder. [2] At baseline these patients also have a high incidence of other chronic diseases associated with tobacco use and physical inactivity such as chronic obstructive pulmonary disease, diabetes, coronary artery disease and peripheral vascular disease. Given the incidence of lung cancer and the associated costs of treatment, a relatively inexpensive and efficacious therapy for reducing symptom burden and optimizing quality of life could be incorporating structured physical exercise into the patient's lives.[3-5] Higher levels of physical activity have consistently been shown to be related to reduced symptom burden, improved quality of life, treatment eligibility for surgical resection and/or chemotherapy, outcomes, and overall survival in cancer survivors.[4,6-9]

There are currently very limited studies that have specifically assessed the outcome of community-based structured exercise programs for lung cancer survivors and none that have been developed taking into account the barriers and enablers of community participation. This is despite the fact that exercise regimens that target individuals within the community have been shown to be markedly beneficial in a number of chronic disease processes including other forms of cancer.[3-5,10]

Our research partnership development award application will use a community-based participatory research (CBPR) approach to build capacity for a lung cancer survivor physical activity research consortium. This partnership will be between a community organization involved in psychological well being and promotion of physical activity for cancer survivors ( ) and academic partners involved in cancer rehabilitation (Shirley Ryan Abilitylab, SRAL) and cancer treatment (Robert H. Lurie Comprehensive Cancer Center, RHLCC). As a first step we will use the award to understand the needs and challenges of lung cancer survivors in the hospital and community setting and also further provide our unique community and academic perspectives to the consortium. This is with the eventual long-term research goal of developing our own physical activity research intervention for lung cancer survivors (which is beyond the scope of this grant).

A. SPECIFIC AIMS AND OBJECTIVES

The creation of a collaborative community based research partnership will be instrumental in developing a future outcomes-based physical activity intervention that is pragmatic in increasing physical activity in lung cancer survivors in the community. The complexity of cancer survivorship is best addressed with support systems at the personal, hospital and community level. GCC's mission statement is to 'ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community' and this is an ideal ethos behind our partnership. Through developing this partnership, our collaborative team strives to target and deliver resources to promote physical activity in the community at these three levels of support (cancer treatment, rehabilitation and community transition and on-going care) that are relevant, feasible and sustainable.

Aim 1: **To build and establish an effective relationship between academic institutions with expertise in cancer care and a community-based cancer support organization**
Together, the partners (academic: Shirley Ryan Abilitylab and Robert H. Lurie Comprehensive Cancer Center and community:) will share prior initiatives, discuss goals and barriers to promoting physical activity participation. We will build research capacity between the community organization (including their satellite sites and community liaisons) and academic rehabilitation and oncology providers.

Aim 2: To ascertain barriers and influences contributing to participation in structured exercise programs specifically among lung cancer survivors
Together, the partners will identify the lung cancer population across the Chicago neighborhoods. We will design and administer a multi-dimensional physical activity needs assessment in various community settings including at the RHLCC, and ethnic and faith based organizations.

B. BACKGROUND AND SIGNIFICANCE

1. The Benefits of Physical Activity in Lung Cancer

The American College of Sports Medicine recommends that healthy adults participate in 150 minutes of moderate intensity physical activity per week.[8] Regular physical activity has also been shown to improve performance status in patients with cancer which is a marker used to determine eligibility for treatment.[11] Higher levels of physical activity in lung cancer survivors are related to reduced symptoms, improved quality of life, treatment outcomes and survival. [4,6-9] There is a clear need for adequate physical activity participation in lung cancer survivors since it has marked implications on prognosis, treatment eligibility and overall survival rate. Unfortunately only 30% of those with lung cancer meet these physical activity guidelines at the time of their diagnosis, which likely worsens as they continue treatment. Engaging these individuals in exercise and improving their lifestyle choices following their diagnosis can be particularly challenging.[12,13] Lung cancer survivors are an especially vulnerable population reporting higher levels of pain, breathing difficulties and fatigue compared to other types of cancer. ***No prior study has used a community based participatory research (CBPR) based approach to understand the personal and environmental barriers to physical activity participation specifically in a lung cancer population. This is despite the fact that lung cancer is the most common cause of cancer related death and that physical activity has been shown to be of significant benefit to this population.***

The barriers to physical activity participation in those with chronic diseases include high symptom

burden, knowledge gaps to implement a feasible exercise program, attitudes towards exercise, environmental and socioeconomic pressures and access to exercise programs themselves.[14] The majority of physical activity programs targeted at cancer survivors have been administered in structured, supervised hospital settings. Unfortunately these do not often take into account the community barriers and needs pertaining to exercise and access to these programs, which in turn affects compliance and ultimately outcome.[14,15] Recent evidence suggests that community based exercise programs could be particularly beneficial in subjects with chronic diseases, providing direct access, structure, peer support, mentorship and more engagement leading to improved compliance in these programs. In addition these programs in cancer survivors in particular can improve aerobic capacity, flexibility and strength.[3] ***Lung cancer survivors would likely benefit from these community based programs since fewer are now hospitalized for treatment and therefore the community environment is a practical setting to promote physical activity. In addition it is pivotal to address this in survivors in the community because higher levels of activity have treatment eligibility, prognostic and survival implications.***

2. Our Proposal Within the Wider Context of Chicago Public Health Priorities

Lung cancer is a significant problem for the city of Chicago with an incidence in the city of 66 per 100,000 people, remaining the leading cause of cancer related deaths in Cook County.[16] There are also significant geographic, socioeconomic and racial disparities in cancer related deaths (1.2 for every 1 between Africa-American: Caucasians, with the majority from a lower socioeconomic background).[16] As shown in figure 1 – data from the Chicago Health Atlas shows there is also a geographical disparity in lung cancer incidence with a higher incidence in the less affluent neighborhoods.

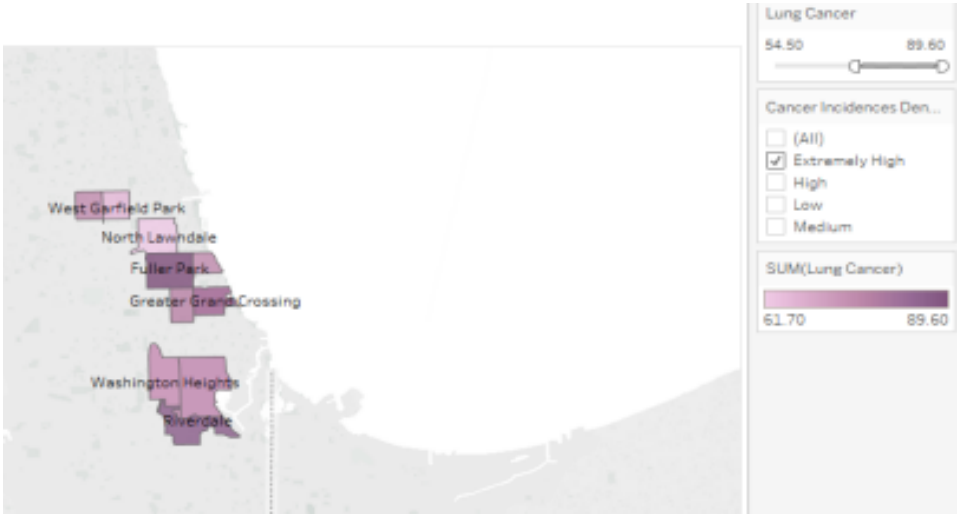

Figure 1 – Areas with very high lung cancer incidence include Fuller Park, Riverdale and Washington Heights

Mirroring the cancer incidence, physical activity participation in adults in Chicago is sub-optimal and worse in the less affluent areas of the city. The Healthy Chicago 2.0 survey of Chicagoans reported that 18.3% engaged in "no physical activity." The 2016 Northwestern Memorial Health Care's Community Health Needs Assessment (NMH CHNA) found similar results in that 20.5% of all patients reported no leisure time physical activity. Physical inactivity was higher among adults over the age of 40, lower-income residents (25.4% lower income residents vs. 13.5% higher income residents), African-Americans and Latinos (NMH CHNA).

The 2016 NMH CHNA dataset identified access to health services and physical activity as two priority health needs. Additionally, tobacco use (which is highly associated with lung cancer) and activity limitation were identified as areas of opportunities The report also stated that, individual beliefs in the ability to exercise, social support from peers, access to and satisfaction with facilities are facilitators of physical activity. Our proposed research partnership fits well within the scope of priorities of health needs of the NMH CHNA and Chicago as a whole. Although never fully delineated, the barriers to physical activity participation in lung cancer survivors are likely multi-factorial and need to be adequately addressed. **Forging a community based partnership among academic and community organizations to identify determinants of physical activity**

participation in lung cancer survivors would help create an efficacious multi-faceted approach to promote physical activity in this medically complex, highly vulnerable patient population.

C. ESTABLISHING THE PARTNERSHIP AND TEAM TRAINING

We believe to achieve the long-term goal of a research consortium for physical activity in lung cancer survivors, as a first step we need to develop and build capacity for a community based participatory research (CBPR) partnership between three stakeholders:

1) A community based organization for cancer survivors with experience in physical activity programs and healthy lifestyle promotion ( )
2) An academic institution that provides physical rehabilitation for cancer survivors (Shirley Ryan Abilitylab)
3) An academic cancer treatment center (Robert H. Lurie Comprehensive Cancer Center).

This collaborative approach will leverage the skillsets and experience of each of the stakeholder's in physical activity promotion for cancer survivors at every stage of their continuum of care making for an efficacious community based research partnership.

Methods/Approach:

The proposed partnership aims to build on the skills and research needs of the organizations, the communities they serve and the skill sets of the co-PIs and co-I. For each individual aim we will construct the following agenda outlined below.

Aim 1

Meetings: In preparation for this grant award application we have already had regular monthly meetings between the partnering organizations and investigators to set the groundwork which we will continue. The location of the meetings during the award itself will be rotated between the primary facility of the community organization ( ), and the academic institutions involved (SRAL and RHLCC). Meetings will be chaired by both Co-PIs and will also be attended by the other co-investigators, residents already involved from the department of Physical Medicine and Rehabilitation at Northwestern University, staff at , with potentially the addition of oncology fellows at RHLCC. The initial meetings will be focused on our respective individual backgrounds and priorities in terms of our collaborative work, introducing the concept of a research consortium in this specific scientific domain and developing a shared vision for collaboration in research. Further meetings will focus on investigator/organizational experience with physical activity in lung cancer survivors, brainstorming on how best to engage them based on assessment of the results of focus groups and surveys as outlined below. Meetings towards the end of the year will be focused specifically on the development of our intervention using the data we have collected as a talking point. In addition has minority outreach officers in the African American and Latino communities with experience in some of the neighborhoods that we may need to target, and also the cultural community beliefs that guide behaviors and thus provide perspective on potential challenges. As well as running 's programs within certain hospitals in the city, the minority officers are involved in outreach to specific cultural and faith based organizations.

Seminars/guest lectures: We will have expert speakers who will give short presentations in certain topics that will be pivotal in us developing a longer-term research project. These speakers who we have already reached out to will be experts in the areas of CBPR, statistics, outcomes research, motivational interviewing, cancer rehabilitation and physical activity programming from Northwestern University and the associated outside community. As we will be learning together from these experts, we believe this strategy will also further forge our partnership and camaraderie as a research team.

Workshops: Within 's educational programming, academic collaborators from SRAL and RHLCC will deliver quarterly collaborative workshops. These workshops will be tailored towards lung cancer survivors and focus on physical activity guidelines. During these workshops surveys will be provided to lung cancer survivors to assess some of the barriers and enablers of physical activity participation in these attendees who are already engaged in programming.

Aim 2

We will assess the barriers and facilitators to physical activity participation across the continuum of care both in the hospital and in the community.

Lung cancer clinic survey: We will formulate a short survey that will be given to lung cancer survivors undergoing active treatment attending the RHLCC thoracic oncology clinics. We anticipate that this will give us an understanding of the issues that lung cancer survivors face with physical activity earlier in the continuum of care. The survey will also address the lung cancer patient's perception of their disease and psychological wellbeing.

Focus groups: will host focus groups for lung cancer survivors (that we will collectively observe) tailored towards understanding the barriers and enablers to physical activity in this population. These individuals will discuss their feelings towards physical activity interventions and also discuss the types of physical activity interventions that would work for them in the context of their disease and limitations. We will have 4 focus groups throughout the year, which will be stratified by current exercise levels (i.e. two focus groups tailored towards those currently engaged in exercise and two on those who are not). Each focus group will have up to 10 participants and will be audiotaped with participant consent. To facilitate the discussion the two PIs will develop a structure to the focus group. From current literature, topics that would be discussed include: 1) levels of physical activity both pre- and post-diagnosis 2) knowledge of current physical activity guidelines and their benefit 3) barriers and facilitators towards physical
activity 4) psychological well being of participants.

All three collaborating organizations will recruit volunteers for the focus groups via flyers posted in their respective buildings/clinics and community outreach. has a strong history of hosting such focus groups giving those with cancer an opportunity to discuss their disease and hence they will host them. Focus group participants will be paid $15 for their time, and it is anticipated that the focus group will be a maximum of 1.5 hours.

Dissemination: – All stakeholders will be responsible for disseminating the results. Both Co-PIs will assist in writing a report for each aim which we envisage will be a manuscript each that could be submitted to a peer reviewed journal. As an entire team we will discuss how best to disseminate the research findings as well discuss with prior ARCC funded investigators.

D. SUSTAINING THE PARTNERSHIP AND FUTURE RESEARCH

Assessment of a current GCC Physical Activity Program

As a step towards sustained and future collaboration, part of this award will also include an outcomes evaluation of a current physical activity program at . has a cancer survivor boot camp at Medical Center that consists of a 7-week program of 14 sessions of
one hour of exercise aimed at improving aerobic ability, fitness knowledge and commitment to a healthy lifestyle. These sessions incorporate a variety of exercise styles including yoga, weight training and Zumba. has not previously assessed the outcome of these programs and since these are similar to the type of intervention we would like to create for lung cancer survivors, the assessment will be an opportunity to perform a pilot assessment putting into action the skills we would have collectively learned during the time of the grant award.

Infrastructure

(Co-PI) as the Director of Special Initiatives at . This organization supports anyone living with any type of cancer – men, women, teens and children – along with their family and friends. The innovative program, including more than 350 free activities each month, is an essential complement to medical care and offers physical activity programming, support groups, educational lectures, healthy lifestyle workshops, resource referrals and social opportunities. is a non-profit organization funded through donations from individuals, businesses, foundations and special events. It is the Chicago affiliate of the Cancer Support Community – a worldwide network of more than 50 affiliates and 100 satellite locations, as well as a provider of online resources. All programs are free and participants are given the opportunity to complete a Customized Membership Plan

(CMP) with the help of a licensed mental health professional and can take part in more than 350 individual activities each month. In addition to the downtown Clubhouse, also operates in five hospital satellite locations throughout the Chicagoland area including RHLCC. Therefore they have a history of working with the partnering organizations and with their experience and ethos of physical activity promotion in the community they are the ideal collaborator for this project.

MD, PhD (Co-PI) is a Steering Committee Member of ARCC, and an Assistant Professor in Physical Medicine and Rehabilitation at Northwestern Feinberg School of Medicine and an attending physician at **SRAL** with extensive background in physical activity for chronic musculoskeletal conditions. He currently has funding for an NIH-K12 award to investigate the development of walking exercise regimens for knee osteoarthritis. Dr is an attending at the Shirley Ryan Abilitylab (formerly called the Rehabilitation Institute of Chicago (RIC)). This is a state of the art rehabilitation facility with resources available that
include clinical examination areas to conduct research, participant assessment and laboratories. It brings together high quality comprehensive care for individuals with disability, research into the mechanisms and management of disabling conditions and training of professionals and the public about disability and approaches to its management.

MD (Co-I) is an Associate Professor at Northwestern Feinberg School of Medicine with over 20 years experience in thoracic oncology with a specific focus in the management of lung cancer. She is an attending physician at **RHLCC** is one of only 47 National Cancer Institute-designated Comprehensive Cancer Centers in the nation. In addition, the Lurie Cancer Center is a founding member of the National Comprehensive Cancer Network (NCCN), an alliance of 27 of the world's leading cancer centers dedicated to quality, effectiveness, and efficiency of cancer care so that patients can live better lives

Future research and external funding

Deliverables – In the short-term we plan to use the surveys taken both in the community and hospital settings of lung cancer survivors as research tools that we will present at national meetings and submit for publication. Therefore we will apply for Institutional Review Board clearance for these surveys.

Research Grants – Our long-term goal in research is to develop a physical activity intervention to improve the symptom burden, quality of life and psychological well-being of lung cancer survivors. We initially will apply for a Foundation Award from the Foundation for PM&R New Investigator Award funding mechanism and will also apply for an ARCC research engagement grant to collect pilot data. We then in the long-term plan on applying for an NIH R21 from the National Cancer Institute (PAR-16-123) in which the request for applications focuses on 'Physical Activity and Weight Control Interventions Among Cancer Survivors.

Cancer Support Community Research and Training Institute (CSCRTI) is the Chicago affiliate of this organization. Launched in 2008, the Research and Training Institute (RTI) is the first institute dedicated to cancer related psychosocial, behavioral and survivorship research and training. The Institute seeks to examine the critical role of emotional and social support in improving the lives of people facing cancer, and to share what they learn with the broader cancer community. The goal is to assure that patient and caregiver voices are heard by bringing scientific rigor and evidence-based research together with innovative approaches to collecting, evaluating and disseminating our findings. They bridge the gap between research and practice by using the information and insight from our community to improve Cancer Support Community programs and raise awareness of emotional and social issues with health care providers and policy makers.

will have access to the findings specifically from the Cancer Experience Registry the primary focus of which is to collect, analyze and share information about the experience and needs of patients and families throughout their cancer journey. This will also allow us to find novel avenues of research that will be available to our consortium.

Maintaining future Collaboration

Our plan in creating this research partnership is that this is a long-term endeavor. By incorporating people with differing expertise both in academic and community organizations we will learn from

each other. All academic members of the proposal remain committed to the development of future grants and research opportunities. The research consortium we will create covers patients from their lung cancer diagnosis in the oncologist's office, their physical rehabilitation to their integration within the community. This will allow us to create a network that encompasses a larger continuum of care both in the hospital and in the community that we believe will be efficacious. To generate new research enterprises, we will also include novel collaborators in to the consortium through recruitment both in the community and our academic institutions. currently has a staff member who is based out of the RHLCC and recruits for their programs, and it is our aim that by showing the benefit of our research consortium we will also get a further staff member from based at the Shirley Ryan Abilitylab dependent on funding availability.

Potential hurdles and limitations

The main hurdle that we envisage would be involving conflict operationally or during decision making. Using a CBPR model, the community and academic co-PIs will steer the development of rules and operating procedures during the meetings to promote partnership effectiveness. All meetings will have set structure, goals and rules of engagement outlined at the beginning. We anticipate there maybe conflicts and we see this as essential to growth and if necessary we will setup sub-committees with specific smaller tasks pertaining to our aims. Another potential limitation of our work is lung cancer survivors themselves with high chronic disease burden. They have a low physical activity rate at baseline and so we anticipate engaging this population in physical activity will be challenging, but it is our hope by using a CBPR model of building capacity we can achieve this.

Timeline

MONTH	1	2	3	4	5	6	7	8	9	10	11	12
Partnership Meetings	X	X	X	X	X	X	X	X	X	X	X	X
ARCC workshops			X		X		X		X		X	
Organize and recruit focus groups	X	X	X									
Perform focus groups			X		X		X		X			
Review results of focus grouos				X		X		X		X		
CBPRcurriculum review	X	X	X									
Identify & meet w faith & ethnicorgs		X	X	X								
Develop needs assessment surveys				X	X	X						
AdministerNeeds assessment						X	X	X				
Evaluate Needs assessment results								X	X	X		
Combination Lecture/Workshop			X					X				
Develop outcomes assessment for 'boot camp'							X	X	X			

Develop next grant application									X	X	X	X

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NUCATS/ARCC RESEARCH PARTNERSHIP DEVELOPMENT GRANT PROPOSAL

Project Title: Community Engagement to Improve Services for People Affected by the Death of a Child

Aims

In 2017, roughly 1250 children and young adults will die in Chicago and Suburban Cook County. Childhood deaths reverberate broadly through their impact on families, schools, neighborhoods, faith based communities, and healthcare providers. Childhood death imposes special challenges for bereaved survivors who are at risk for complicated grief, depression, anxiety, poor physical health, and increased mortality.[1, 2] Unfortunately, Chicago suffers from inadequate access to and delivery of bereavement support services, leaving those affected by childhood death to grieve without help.

Families access bereavement support through palliative care organizations, hospitals, and community programs. Unfortunately, access to available services is inconstant across different populations. One study found that bereavement support access is more likely for caregivers of patients enrolled in hospice only programs (as opposed to hospice/palliative care programs) and that there is a need for more culturally-appropriate, targeted services for African Americans.[3] Another study found that men and caregivers losing a child having limited access to care.[4] In Chicago, coverage gaps in palliative care persist for both hospitalized and non-hospitalized pediatric patients, and not all hospitals provide bereavement support services. Furthermore, there is no systematic approach or organization that links Chicagoland families of children not followed by a palliative care provider or who experience sudden, unexpected death with bereavement support. Additionally, little empirical data exists to guide best practices for delivering bereavement support. A recent review, concluded that it is impossible to recommend any intervention based on evidence of sufficient quality. [2] Research is desperately needed to guide the development and study of interventions for people affected by childhood death.[2]

Our long term goal is to ensure that anyone affected by childhood death has access to quality bereavement support services. This research partnership development grant proposal will support preliminary steps needed to develop a coalition of stakeholders (individuals, community based organizations, healthcare organizations, healthcare experts, and researchers) dedicated to improving access to and quality of bereavement services through research and program development. We will:

Aim 1. Establish a coalition of community and academic stakeholders interested in improving bereavement services in Chicago for those impacted by the death of a child.
Method: We will identify relevant stakeholders through existing relationships, group input, and support from the Alliance for Research in Chicagoland Communities (ARCC). Through a series of five meetings we will build relationships and trust, and share experiences and expertise in order to refine and finalize the coalition's goals, mission and vision statement, title, organizational structure, partnership roles and responsibilities, and policies and procedures.

Aim 2. Obtain preliminary information about current bereavement support services in Chicago.
Method: Through group discussion we will obtain information about current bereavement support services in Chicago. This first step will start to identify unmet needs and barriers to support.

Aim 3. Explore stakeholders' interest in and capacity needs for conducting bereavement research.
Method: During meetings, stakeholders will discuss their interest in, experience with, and limitations for conducting research. Stakeholders will identify research projects of interest, then chose a research question and design a study around the question of interest. Stakeholders will identify potential funding opportunities and plan future steps for engaging in research.

At the end of this project we will have established a coalition of interested stakeholders poised to obtain funding for future research and identify potential program development projects.

Description of partnership

Co-Principal Investigators

The co-principal investigators, Ms. and Dr. bring a cumulative 35 years of experience in clinical research and bereavement support to this project. They have a track record of collaboration both as colleagues and through their respective organizations.

Ms. , a LCPC in Counseling Psychology, is the current Program Coordinator (since 2016) at the is a nonprofit, 501 (c)(3), Illinois organization interested in improving access to quality, community-based, pediatric palliative care services. (See www. .org.) coordinates collaborative educational and clinical improvement projects to further the mission. Non-profit, community-based, palliative care programs make up about 75% of 's total membership. Other members include children's hospitals, organizations that support children with life-limiting illnesses and their families and individual community members.

Prior to joining , Ms. spent 15 years as the program director of the Ann & Robert H. Lurie Children's Hospital of Chicago bereavement program, . In this role she conducted phone consultations, provided information/literature to families, organized and conducted family support groups and clinician educational sessions. She has also facilitated bereavement trainings for numerous schools, social service agencies, and healthcare systems. While at Lurie Children's, she worked with Dr. to develop a bereavement photography program for families of children who die in the pediatric intensive care unit (PICU).[5] Ms. was also a stakeholder on a Patient Centered Outcomes Research Institute (PCORI) funded project led by Dr. .

Dr. is Associate Professor of Pediatrics, Professor in Bioethics and Medical Humanities, Director of the Center for Bioethics and Medical Humanities at Northwestern University Feinberg School of Medicine, and attending physician in Critical Care Medicine at Lurie Children's Hospital. Dr. 's research focuses on PICU decision making, pediatric palliative care, and bioethics. She utilizes qualitative and quantitative methods, community based participatory research, and stakeholder engagement. She has received funding from the National Institutes of Health, PCORI, the American Cancer Society, and the National Palliative Care Research Center.

Dr. has worked with for over 5 years. In 2013, Dr. and co-principal investigator Ms. , then the program director, received an ARCC seed grant to study a pediatric palliative care needs assessment tool. This work involved collaboration with 3 Chicago community based pediatric palliative care organizations, and (with permission from ARCC) a New York pediatric palliative care program. Results from this project were presented at the 2016 American Academy of Hospice and Palliative Medicine annual conference. We expect to submit the manuscript for this work by the summer 2017.

Ms. and Dr. have often discussed the limits to existing bereavement support in Chicago. While the death of a child is unimaginable, for nearly 1300 families a year in Chicago, it is a reality. Families of children who die and were cared for by Lurie Children's Hospital physicians benefit from an organized bereavement support program that includes regular mailings with supportive and educational literature, phone contact with bereavement specialists, and options for participating in Lurie Children's Hospital organized support groups. But empirical data do not exist to support this approach to bereavement services.[2] Moreover, families at many other Chicagoland hospitals are simply sent home with nothing, literally empty arms, when their child dies. Families must find their own support programs and in many neighborhoods, such programs are nonexistent. Certainly, some organizations offer limited services such as follow-up with a condolence card or phone call, and others (like Lurie Children's Hospital) have highly-designed protocols that supports bereaved families for several years. But there are no standards. Finally, while no Chicago-based data exists, we have strong concerns that lower income neighborhoods have limited or absent access to formal professional bereavement support programs. We strongly feel that a family's ability to access high quality support should not depend on what neighborhood they live in.

This project seeks to address these inequities in access to and delivery of bereavement support services, as well as develop a structure for conducting research that would add to the now limited literature in this area. We will to do this by establishing a community based coalition of diverse stakeholders. The potential benefits of such an organization include:

• Capacity to develop citywide collaborative efforts supporting bereavement needs for those affected

by childhood death
• Establish a broader voice from which to advocate for needed bereavement support programs • Engage diverse stakeholders to develop novel approaches for families and communities coping with childhood death
• Establish an organizational framework for providing centralized, standardized bereavement support for families of children who have died to augment or fill in gaps of existing services • Conduct research that develops and evaluates the impact of bereavement support services We will use a process of participatory engagement with community organizations, parents, and clinicians, cultivating existing relationships and exploring new partnerships as described below.

Existing relationship

To engage potential coalition members, we will start by soliciting support from and inviting participation of people and organizations with whom Ms. , , and Dr. have existing relationships. These include the following people/organizations:

Parents who have experienced the death of a child. Dr. has worked extensively with 5 bereaved parents (Ms. , Ms. , Ms. , Mr. , and Mrs.) as research stakeholder team members for her PCORI funded project. Ms. has relationships with bereaved parents through her 15 year tenure as bereavement coordinator at Lurie Children's Hospital and through . Ms. and Dr. can also work with Lurie's Heartlight staff to identify and extend invitations to additional parents. We will seek parents with from diverse racial/ethnic backgrounds (e.g. Latino, Asian, and Black) and men. We anticipate involving 6-8 parents.

Representatives from Chicagoland pediatric hospitals. We will reach out to the following people that either Dr. or Ms. have worked with to identify appropriate hospital representatives.

Name	Title	Institution	Contact Info
, MD and/or , RN	Director of the Pediatric Palliative Care Program (summer 2017) Neurosurgery PNP with interest in bereavement	University of Chicago Comer Children's Hospital	
, MD	Assistant Professor in the Department of Pediatric Critical Care and Hospice and Palliative Medicine	Rush University Medical Center	
, MD	Professor and Division head of palliative care	Lurie Children's Hospital	
RN, MSN, CPN, NE-BC	Program Director, Women & Children's Service Lines, Northwestern Medicine Central DuPage Hospital	Central Du Page Hospital	
, M.D. and/or , MS, APN, PCNS-BC, CHPPN, FPCN	Medical Director, Pediatric Palliative and Supportive Care & the Palliative & Supportive Care Center for Fetal Care Advocate Children's Hospital	Advocate Children's Hospital, Oak Lawn and Park Ridge	

Community based pediatric palliative care organizations in Chicago. , provides the majority of community based pediatric palliative care in the Chicagoland area and is the largest pediatric palliative care community based program in the Midwest. We will contact Dr. , Pediatric Medical Director at and board member, who has expressed support for this project.

Funeral home representative. is a former lawyer and co-owner of , the Cremation Company. She handles all the pediatric deaths in the company and is a Board memeber. She has already expressed interest in participating. In support of this project she noted, "The isolation, that I know I've mentioned

to you before, is so real for many of these families and it would be amazing to have a state-wide program/resource."

Research Expert. Dr. , a PhD and RN researcher with special interest in palliative care and end of life care for children and their families, including bereavement support, is relocating back to the Chicagoland area after teaching at the College of Nursing, Wayne State in Detroit, and UIC. Dr. has also expressed interest in partnering with and Dr. on this project.

Developing New Relationships

We will also reach out to others in the community to develop new relationships and engage the most inclusive and comprehensive group possible. We will seek representation from schools (possibly a Chicago Public Schools representative) and faith based organizations. We will identify these stakeholders with input from our group of existing relationships and from ARCC. We will also contact Dr. Assistant Professor of Counseling at Northern Illinois University. Dr. is relatively new to Chicago (arrived fall 2016). He has a PhD in Counselor Education and Supervision, does research on preschool grief reactions, and is currently conducting a study exploring the grief and loss experiences of children through the lens of the care providers from counseling or support settings. Through conversation with stakeholders, other organizations or representatives may be invited to join as well.

Methods

Outreach to existing relationships. We will organize one-on-one phone meetings with our current contacts (existing relationships) to assess interest in participating in the coalition and availability for group meetings.[Aim 1] These initial phone calls will also provide an opportunity to obtain information about existing bereavement support and ask for input about additional stakeholders to include in the coalition.[Aims 1 and 2] These phone calls will be conducted by Dr. and Ms. .

Identify new relationship. We will consult ARCC to guide identification of additional stakeholders. Likely additions will include representatives from the Chicago Public Schools and Faith based organizations.

Meetings. We will convene stakeholders through a series of meetings. Anticipated participants and agenda items for each of these meetings are described below (with the addressed aim noted in brackets). All meetings will begin with introductions (to enhance team building (TB)) and a review of the previous meeting's activities. Meetings will end by planning the next meeting logistics and future steps.

Meeting 1 will include available people from our existing relationships above. *(Time 2 hours)*

Agenda:

- Introductions to include stories/information about people's organization, role in their organization, bereavement support, and research involvement [TB, Aims 1 and 2]
- Focused discussion on existing bereavement support services/experience [TB, Aim 2] • Discuss gaps in existing bereavement support services or barriers to accessing existing bereavement support services [TB, Aim 2]
- Consider potential benefits of and challenges to developing a citywide coalition [Aim 1] • Identify additional stakeholders to include in the coalition [Aim 1]

Post meeting 1 activities:

• Ms. and Dr. will create and distribute meeting minutes to all participants. • Ms. and Dr. will reconvene with ARCC to identify additional stakeholders using input from meeting 1. Ms. or Dr. will then conduct one-on-one phone meetings with additional stakeholders to assess interest in participating in the coalition and availability for group meetings.[Aim 1] These initial phone calls will also provide an opportunity to obtain information about existing bereavement support. [Aim 2]

Meeting 2 will include all meeting 1 participants plus new stakeholders identified through consultation with ARCC and input from the previous meeting*. (Time 2 hours)*

Agenda

- Introductions to include stories/information about people's organization, role in their organization,

bereavement support, and research involvement [TB, Aims 1 and 2]

• Focused discussion on existing bereavement support services/experience [TB, Aim 2] • Discuss gaps in existing bereavement support services or barriers to accessing existing bereavement support services [TB, Aim 2]

• Recap of meeting 1 and input from stakeholders not at meeting 1 about potential benefits and challenges to developing a citywide coalition and additional discussion if needed [Aim 1] • Consider need to include additional stakeholders in the coalition [Aim 1]

• Discuss possible goals of the coalition [Aim 1]

• Explore stakeholders' interest and experience in research. [Aim 3] We address the following: ○ What are the organization's/community's/individuals' views about doing research? ○ How have you/your organization used research before?

○ How does you/your organization currently use research?

○ Stakeholders' will be asked to complete a version of the ARCC Assessment tool included in the document, "Assessing your Organization's Research Environment/Capacity" modified by Dr. and Ms. . If necessary this could be completed online following the meeting.

Post meeting 2 activities:

• Ms. and Dr. will create and distribute meeting minutes to all participants. • Ms. and Dr. will create a list of existing bereavement support services, gaps in services, and barriers to accessing services based on input from phone calls and meetings 1 and 2. • Ms. and Dr. will create a preliminary list of coalition goals

Meeting 3 will include stakeholders with continued interest in the coalition identified via meetings 1 and 2 *(Time 2-3 hours, to be determined by group consensus)*

Agenda:

• Consider changes to the list of coalition goals described in previous meeting [Aim 1] • Begin discussion of coalition mission and vision statement and coalition title [Aim 1] • Discuss utilizing the coalition to engage in research [Aim 3]

○ Dr. to provide an overview of the research process, and describe community engaged research and how it differs from other research using relevant parts of the ARCC "Introduction to research: Developing a research question" document

○ Group SWOT (strengths, weaknesses, opportunities, threats) analysis related to conducting research • Do group concept mapping exercise (per ARCC "Introduction to research: Developing a research question" document) to identify potential topics of interest for future research. [Aim 3]

Post meeting 3 activities:

• Ms. and Dr. will create and distribute meeting minutes to all participants. • Ms. and Dr. will create an updated list of coalition goals.

• Ms. and Dr. will create a draft of the coalition's vision and mission statements and title. These will be distributed to coalition stakeholders via email for additional input and editing. • Ms. and Dr. will consult ARCC for input on how to address any research capacity building needs identified during meeting 3. (E.g., obtaining Federal Wide Assurance numbers for organizations that do not have them, considering the need for institutional agreement contracts with participating organizations, providing options to obtaining education in human subjects research for those new to clinical research)

Meeting 4 will include the same people as Meeting 3. *(Time 2-3 hours, determined by group consensus)*

Agenda:

• Consider changes to the list of coalition goals described in previous meeting [Aim 1] • Discussion of the coalition mission, vision, and title. [Aim 1]

• Begin to develop an action plan for the coalition using the structure in the ARCC document "Developing a Research Action Plan for Your Organization" as a model. This will include a discussion of the coalition's organizational structure, roles, responsibilities, and needed policies. [Aim 1] We acknowledge that this ARCC document is focused on developing a research action plan but feel there are components useful to developing an organizational action plan for the coalition.

• Prioritize research topics and identify a topic for first research project. [Aim 3] • Begin discussion

of study design for identified research topic of interest. [Aim 3] ○ Use the ARCC document entitled, "Introduction to research: Developing a research question" to develop a research question that is feasible, interesting, relevant and ethical.

• Identify organizational or personal limitations for conducting research around the identified topic of interest. [Aim 3]

Post meeting 4 activities:

• Ms. and Dr. will create and distribute meeting minutes to all participants. • If not yet finalized, Ms. and Dr. will distribute the coalition's near-final vision and mission statement and title via email for additional input.

• Ms. and Dr. will create a preliminary draft of the coalition's memorandum of understanding (MOU) based on the meeting 4 discussion and distribute this preliminary draft to coalition stakeholders via email for input and editing.

• Ms. and Dr. will re-consult ARCC for input on how to address any research capacity building needs identified during meeting 4.

Meeting 5 will include the same people as Meeting 3. *(Time 2-3 hours, determined by group consensus)*

Agenda:

• Review current version of MOU based on email input and consider edits as needed [Aim 1] • Continue discussion about study design for identified research topic of interest [Aim 3] • Discuss approaches to research capacity building needs identified during meeting 4. [Aim 3] • Identify funding mechanisms for program develop and research. [Aim 3]

• Plan next steps

Post meeting 5 activities:

• Ms. and Dr. will create and distribute meeting minutes to all participants. • Ms. and Dr. will email the group with near final MOU for input and then obtain signatures on final version of the MOU.

• If possible/needed Ms. and Dr. will operationalize activities to enhance research capacity among the group.

• If possible Ms. and Dr. and any other interested coalition members will begin developing a grant proposal for subsequent funding.

Timeline and milestones/measures of success

The project timeline, planned milestones, and expected deliverables are described in the table below.

Milestones	Deliverable	1	2	3	4	5	6	7	8	9	10	11	12
Outreach to existing relationships	• List of participants for meeting 1	x											
Meeting 1	• Meeting 1 minutes		x										
Identify new relationships	• List of new participants for meeting 2	x	x	x									
Meeting 1	• Meeting 1 minutes		x										
Meeting 2	• Meeting 2 minutes • List of bereavement support services, gaps, and barriers				x								
Meeting 3	• Meeting 3 minutes						x						
Meeting 4	• Meeting 4 minutes • Coalition title, vision and mission								x				

Meeting 5	• Meeting 5 minutes • MOU • Preliminary research project topic • List of potential funders									x	x	*

*Meeting 6 if needed

Adherence to the Center for Community Health Principles of Engagement

We will adhere to the Center for Community Health Principles of Engagement in the following ways:

- *Collaboration:* Through iterative conversations, largely during meetings but also via email, we will develop a shared vision. We have included activities specifically aimed at building trust and developing partners' capacity.
- *Respect:* While we have some idea about directions and goals for both the coalition and future research, ultimately activities will be determined based on stakeholder priorities identified through conversation and listening. In doing so we will place specific attention on including and recognizing the needs of people from different perspectives and cultures
- *Equity:* Approaches to ensuring issues related to equity, such as sharing power, resources, engaging in decision making, and addressing conflicts will be determined by group consensus and documented in our MOU.
- *Transparency:* As described above we have planned for frequent, comprehensive communications with stakeholders. Additionally, the goals and priorities for the coalition will be determined by group consensus.
- *Impact:* As described above all information will be shared with partners and stakeholders. With group consensus we will identify meaningful/sustainable outcomes. Approaches to dissemination of future results or plans will be determined by group consensus.

Potential Hurdles or limitations and how addressed

Because we aim to include a relatively large group of stakeholders (likely around 20), we may encounter difficulty accommodating schedules and overcoming geographic barriers. To address this we will rotate meeting locations. We will convene the first meeting at Lurie Children's Hospital, and subsequent meetings at other stakeholder locations based on interest and availability. In other words, subsequent meetings may take place at or University of Chicago or a Church. We feel it will be important to meet in person, ideally for the first two meetings, but will provide the option for people to attend meetings 3-5 via phone or video conference (using Zoom). We will provide minutes after each meeting with a summation of the discussion for those unable to attend. We will also engage participants in multiple activities via email between meetings as described above.

There may be differences of opinion about the scope of the population for the coalition to address. For example, some may feel that addressing the needs of families impacted by sudden unexpected death as a result of trauma or violence should be a focus or at least part of population the coalition seeks to support. Others may feel that the coalition should focus on families impacted by the death of a child as a result of a medical condition. Ultimately, we hope resolution of divergent opinions will be guided and determined by group input. Part of our preliminary discussion will include a process for addressing divergent opinions, such as developing a subcommittee. Also, it is possible that the people we contact will not be interested in this project or able to participate. However given the expressed interest in people we've already contacted, we feel this is unlikely. Similarly, some may not feel like engaging in research should be a primary coalition activity. While unfortunate, this would be good information to have as Ms. and Dr. consider future research opportunities. Finally, 5 meetings may not provide enough time to complete all the planned activities. If necessary we will organize a 6th meeting and have allowed time for this in our time line.

Expected outcomes/future plans

This work will lead to three outcomes: 1) a coalition of multidisciplinary diverse community members seeking to improve access to and quality of bereavement support services for people in Chicago impacted by the death of a child; 2) preliminary data about existing bereavement support services in Chicago; and 3) a focus and preliminary design for the coalition's first research project. Possible first

research projects may involve conducting a bereavement support services needs assessment or obtaining input about preferred types of bereavement support programming from additional relevant stakeholders. Future plans will involve efforts to: 1) sustain the coalition; 2) define and fund program development based on existing needs identified by the group; and 3) engage in collaborative research. All three of these will require additional support. The group will identify potential funders for future work. A preliminary list of possible opportunities include: ARCC's Engaged Research Project Development Award; the National Palliative Care Research Center pilot/exploratory grant mechanism; the NIH (for example, current funding opportunity PAR-16-250, Building Evidence: Effective Palliative/End of Life Care Interventions); the New York Life Foundation Grief Research Grant, developed in conjunction with the National Alliance for Grieving Children; and the Walmart Foundation's State Giving Program, an award to support programs that focus on the unmet needs of underserved low income populations.

Attention to priority needs

This project addresses multiple priority needs. First, attention to bereavement support can impact complicated grief, a mental health diagnosis described in the DSM-V, as well as depression, anxiety and other mental health issues. Mental health is one priority area identify by Northwestern Memorial Hospital. In the Northwestern Community Health Needs Assessment of 2015, it was noted that depressive disorders are notably high among women and adults between the ages of 40 and 64, a cohort that describes many parents affected by childhood death. This report also highlights that depressive disorders are high among very low income residents, a group that we worry have inadequate access to bereavement support. Second, this project seeks to improve access to bereavement support services. This aligns with the finding from the Northwestern Community Health Needs Assessment of 2015 indicating that access to healthcare services is a key priority issue. It also aligns with reports from the Chicago Department of Health Healthy Chicago 2.0 - Community Health Assessment which identified issues around access to healthcare. Finally, while we don't have good information about existing bereavement support services, something this work will begin to develop, we have significant concerns about inequities in support among some Chicago communities. Thus this work addresses ARCC's goal of engaging Chicagoland communities experiencing health inequities.

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BUDGET CATEGORY	SUPPORT REQUESTED		
	Community Co PI Funds	Academic Co-PI Funds	Total
Personnel			
Community Co-PI	1,200		$ 1,200
Academic Co-PI		1,500	1,500
Project Coordinator	700		$ 700
Community Consultant			$ -
Academic Consultant			$ -

			$ -
Sub-total: Personnel	**1,900**	**1,500**	**$ 3,400**
Non-Personnel			
Consultant Fees			$ -
Meetings	1,550		$ 1,550
Equipment			$ -
Travel/Mileage			$ -
Supplies	50		$ 50
			$ -
Sub-total: Non-Personnel	**$ 1,600**	**$ -**	**$ 1,600**
TOTAL EXPENSES	***Total Requested***		
	$ 3,500	**$ 1,500**	**$ 5,000**

Budget Justification

Community Co-PI Funds

, LCPC. (1.25% effort) Ms. is the Program Coordinator at the . Ms. shares responsibility with Dr. for overseeing this project. Ms. will work with Dr. to reach out to new and existing relationships for participation in the project, conduct group meetings, create meeting minutes, and correlate and organize input during meetings to be shared with stakeholders via email and at subsequent meetings. Ms. s will participate in consultations with ARCC to identify new relationships for this project. Ms. will participate in the writing and editing of all deliverables and any subsequent projects including grant proposals. Ms. will also oversee the work of during the study period.

. (1.68% effort) Ms. is an administrative assistant at . Ms. will be responsible for coordinating all study meetings. This will entail, reserving meeting space, obtaining parking passes, sending meeting invitations and reminders, keeping notes during meetings, creating a preliminary draft of meeting notes to be edited and approved by Ms. s and Dr. , organizing all meeting materials (pens, handouts, flip charts, markers). Ms. ’s work will be overseen by Ms. throughout the project.

Meeting expenses. We have budgeted $1550.00 for meeting expenses. This will cover parking for the 5 meetings estimated at $10/person x 20 people x 5 meetings (total $1000). This will also cover the cost of providing lunch for the 5 meetings at $110/meeting (total $550).

Supplies. We have budgeted $50 to cover the costs of supplies including pens, paper, flip charts, or other office supplies.

Academic Co-PI Funds

MD, MPH. (0.45% effort) Dr. n is Associate Professor of Pediatrics, Professor in Bioethics and Medical Humanities, and Director of the Center for Bioethics and Medical Humanities at Northwestern University Feinberg School of Medicine. She is also an Attending Physician in Critical Care Medicine at Ann & Robert H. Lurie Children’s Hospital of Chicago. Dr. shares responsibility with Ms. for overseeing this project. Dr. will work with Dr. to reach out to new and existing relationships for participation in the project, conduct group meetings, create meeting minutes, and correlate and organize input during meetings to be shared with stakeholders via email and at subsequent meetings. Dr. will participate in consultations with ARCC to identify new relationships for this project. Dr. will participate in the writing and editing of all deliverables and any subsequent projects including grant proposals.

Title: Advancing Biomedical Adherence in HIV Care for Men of Color through Community-Research Partnership

Contact information:

Academic Partner

[redacted], PhD, MPH, Co-Principal Investigator

[redacted]

[redacted]

Division of Adolescent Medicine, Ann & Robert H. Lurie Children's Hospital of Chicago

Department of Pediatrics, Northwestern University, Feinberg School of Medicine

Community Partner

[redacted], Co-Principal Investigator

[redacted]

[redacted]

[redacted]

Executive Director

A. Study Aims

The purpose of this project is to strengthen the community-research partnership between Lurie Children's Hospital (Lurie), Division of Adolescent Medicine, a healthcare entity will a mission to promote the health and well-being of adolescents and young adults; and [redacted]), an organization with a mission to promote the health of men of color who are impacted by HIV infection. Together, we seek to promote biomedical adherence to HIV care among a community highly impacted by HIV infection in Chicago – young men of color (i.e., Black and Latino). Young Black and Latino men who have sex with men (YMSM) are disproportionate impacted by HIV infection and, among those living with HIV infection, are less like likely to be adherent to HIV medications (antiretroviral therapy). The effort to identify individuals with HIV infection, link and keep them engaged in care, support adherence to antiretroviral therapy (ART) and suppress viral replication is known as the "HIV care continuum." In this community-research collaboration, we are focused on an often overlooked step in the HIV care continuum – adherence to ART.

This project builds on a partnership between Lurie and [redacted] which began in 2011 with the development and testing of an HIV medication adherence intervention for HIV-positive youth, ages 16-29, known as "TXTXT."[1] [redacted] was an early partner in our efforts to test this intervention, serving as a site to recruit youth at highest risk of poor medication adherence – YMSM of color. In this proposed project, we bring the research development and dissemination project full circle, back to the practice environment at [redacted], to integrate the TXTXT intervention as a permanent program to promote ART adherence in high risk youth. The adoption of HIV specific evidence-based interventions (EBIs) by community-based organizations (CBOs) is challenging, however, the academic field of implementation science (IS) has developed to provide methods to structure and evaluate the implementation process to promote sustainable uptake of EBIs in practice.[2] We propose to use IS frameworks and tools in this project to describe the implementation process, evaluate both the process and the impact on the target population, and leverage this experience for future research collaboration. Towards this end, we aim to do the following:

Aim 1. Strengthen the community-research partnership between Lurie Children's and [redacted] using the community-based participatory research (CBPR) partnership readiness model to structure readiness activities.

Aim 2: Prepare for implementation of the TXTXT intervention at [redacted], by finalizing study measures for implementation process and outcomes, adapting the intervention to the local context at [redacted] and training staff.

Aim 3: Assess the implementation of TXTXT at [redacted] through evaluation of a pilot implementation trial.

> **3a.** We will evaluate the implementation process and outcomes within [redacted] and among N=25 HIV positive TXTXT participants, ages 18-29.
>
> **3b.** As an exploratory aim, we will also implement TXTXT among N=25 HIV-negative participants, ages 18-29 who are taking pre-exposure prophylaxis (PrEP) medication to prevent HIV infection.

Both Lurie Children's and [redacted] are committed to advance the science and practice of biomedical adherence to HIV care and have joined forces for this implementation project. The products of this project will a TXTXT implementation manual for widespread use in practice, an academic manuscript describing the implementation process and outcomes for publication, and the identification of at least one future collaboration project for Lurie and [redacted] via external funding.

B. Background and Significance

Young Black and Latino men who have sex with men (MSM) in the U.S. are disproportionate impacted by HIV infection. Men who have sex with men (MSM) represent about 4% of the U.S. male population, but 78% of all new HIV infections among men.[3] HIV incidence is highest among young MSM (YMSM) aged 13-29, particularly Black and Latino YMSM.[4] This distribution is also evident in the city of Chicago. The HIV epidemic in [redacted]'s service area for the proposed project is among the highest in the Midwest. In 2015, in the city of Chicago, the highest percentage of new HIV infections was among non-Hispanic Blacks, at 54%; there were over twice as many new HIV diagnoses in non-Hispanic Blacks than Hispanics and nearly three times as many new HIV diagnoses among non-Hispanic Blacks than non-Hispanic Whites.[5] Fully 83% of new diagnoses were

in males. The predominant transmission group citywide is MSM, at 76%. HIV infection by age includes 43% ages 20 to 29, 24% ages 30 to 39, 13% ages 40 to 49, and 11% ages 50 to 59.

In addition to disproportionate risk for HIV infection, MSM of color who are living with HIV infection are less likely to be adherent to antiretroviral therapy (ART).[6] Low adherence is problematic because ART suppresses replication of the virus and results in better long term health for people living with HIV.[7] A secondary benefit of viral suppression is that it also prevents onward transmission, as people who are virally suppressed are much less likely to transmit HIV to others.[8] The effort to identify individuals with HIV infection, link and keep them engaged in care, support adherence to ART and suppress viral replication is known as the "HIV care continuum." In this community-research collaboration, we are focused on an often overlooked step in the HIV care continuum – adherence to ART. Correlates of ART adherence among youth include key psychosocial factors, such as co-morbid mental illness, substance use and HIV-related stigma, among other factors [9]. However, the most frequently cited reason for non-adherence among YLH is simply forgetting. In a study of youth living with HIV, (ages 12-24; n=217), 74% reported the reason for missing doses was that they "forgot"[10]. These findings underscore the need for implementation of reminder interventions, including novel intervention strategies such as the TXTXT intervention described herein.

Pre-Exposure Prophylaxis (PrEP), a daily medication taken to prevent HIV infection, is an efficacious prevention strategy among high-risk populations,[11] however PrEP efficacy findings suggest that PrEP adherence is suboptimal, especially among YMSM.[11-13] The community impact of PrEP will depend on utilization among the highest risk groups, including YMSM. One clear challenge is medication adherence. Hosek et al. found in two separate studies (ATN 082; ATN 110), that YMSM have poor longer-term PrEP adherence with protective levels detected in only 20% at week 24 (ATN 082) and 35% at 48 weeks (ATN 110), respectively. More specifically, Black participants in ATN 110 never reached sufficient drug levels for HIV protection (on average) during the entire study, suggesting that the efficacious value of PrEP may be undermined by issues with adherence. We propose to test implementation of TXTXT intervention to increase PrEP adherence among
HIV-negative YMSM who have been prescribed PrEP to prevent HIV infection.

The adoption of HIV-specific evidence-based interventions (EBIs) by community-based organizations (CBOs) is challenging in their often overburdened and under resourced environments, and few are successfully implemented in practice.[14] The academic field of implementation science (IS), has developed to provide methods to structure and evaluate the implementation process to promote sustainable uptake of EBIs in practice.[2] We propose to use IS frameworks and tools in this project to describe the implementation process, evaluate both the process and the impact on the target population (effectiveness), and leverage this experience for future research collaboration.

B.1. Preliminary Studies

Our prior study determined feasibility and efficacy of the TXTXT intervention. In the TXTXT randomized controlled trial (RCT), funded by NIH, adolescents were equally randomized to a two-way, personalized daily text messaging intervention to improve ART adherence vs. a standard of care comparison group (N = 105, HIV-positive adolescents and young adults, ages 16–29). Adherence to ART was assessed via self-reported visual analogue scale (VAS; 0–100 %) at 3 and 6-months for mean adherence level and proportion >90% adherent (90% adherence is the gold standard). The average effect estimate over the 6-month intervention period was significant for >90% adherence (OR = 2.12, 95 % CI 1.01–4.45, p<.05) and maintained at 12-months (6 months post-intervention). Satisfaction scores for the intervention were very high. Based on these findings, the intervention met CDC criteria for good evidence of efficacy.[1] Thus, in this project, we seek to move this EBI to practice.

C. BRIEF DESCRIPTION OF PARTNERSHIP

C.1. Description of partners. The Division of Adolescent Medicine at Lurie Children's Hospital employees a team pediatricians, clinical child and pediatric psychologists, licensed clinical social workers, researchers, and supporting staff to provide the highest standard of medical and mental health services to children and adolescents up to age 25. Additionally, the division expands evidence-based practice through research activities and provides community-based education on adolescent health issues. Research activities within the

Division of Adolescent Medicine are housed within The Center for Gender, Sexuality, and HIV Prevention. The Center works to make the lives of high-risk adolescent populations healthier through clinical care, education and evaluation as well as professional training, research and public health advocacy. The Center strives to partner with like-minded organizations to create an environment where clinicians, academics and scientists can collaborate to design projects with public health significance. Currently the Center is involved as primary awardee or subcontractor on 13 government-funded research projects and programs focusing on the Center's target populations.

[redacted]), formed by volunteers in 2006, is a community based, peer-led, not-for-profit 501(c)(3) organization located on the south side of Chicago, providing confidential, client-centered, and professional health and wellness promotion targeting minority men. [redacted]'s mission is to develop and provide effective health promoting programs and support services, specifically designed to address the health disparities experienced by Black men who have sex with men (BMSM) and other people of color living in Chicago and surrounding communities. [redacted] is well-positioned to collaborate on the proposed project because the agency is a leading provider of services that link vulnerable and underserved populations to care and services. [redacted], a division of the agency, focused on retention and adherence for BMSM. [redacted]'s goal is to identify and apply best practices and effective models for HIV care treatment adherence for BMSM and their serodiscordant PrEP naïve and experienced partners. [redacted] served over 6,500 persons last year.

An additional contributor to this project is the [redacted] project at University of Illinois at Chicago. The University of Illinois at Chicago (UIC), School of Public Health in collaboration with the [redacted]), has launched the UIC [redacted] ([redacted]). This program is set to expand and enhance HIV prevention and care services for Latino/Hispanic and African American young adults between 18 and 24 years of age who attend the University of Illinois at Chicago (UIC), a Minority Serving Institution, and/or live in catchment areas where non-UIC members of this population live. We will work with [redacted] to reach additional ethnic minority MSM who may benefit from the TXTXT intervention.

C.2. History of Partnership. This project builds on a partnership between Lurie and [redacted] which began in 2011 with the development and testing of an HIV medication adherence intervention for HIV-positive youth, ages 16-29, known as TXTXT. Investigators from Lurie developed this text messaging reminder intervention to promote adherence to ART via an initial pilot test and then an RCT, funded by the National Institutes of Health (NIH).[1] [redacted] was an early partner in our efforts to test this intervention, serving as a site to recruit youth at highest risk of poor medication adherence – YMSM of color. These efforts proved to be successful, as the study sample was 81% YMSM of color, mirroring the larger HIV epidemic, and resulting in successful engagement of youth at highest risk of poor ART adherence. This intervention demonstrated evidence of both feasibility and efficacy to promote ART adherence and has been recognized by the Centers for Disease Control and Prevention (CDC) as an evidence-based intervention (EBI) and by the Health Services and Resources Administration (HRSA) for promotion of ART adherence among young men of color. The proposed project will be the first implementation-based collaboration for the TXTXT intervention, which will extend and strength the research-to practice pipeline. *Effective research-community collaboration takes years to establish, thus, we feel that this project is particularly well-timed for the next logical step in our partnership – implementation in practice.*

D. RESEARCH PLAN

D.1. Overview. We will this implementation project over a 2-year period, with initial readiness and preparation activities occurring in year 1 and implementation and evaluation occurring in year 2 (See Table 1). Details regarding each stage of the project, leadership structure, methods, and analysis are outlined below. **D.1.a. Leadership.** This partnership is led by [redacted] at Lurie Children's and [redacted] at [redacted] as the Co-Principal Investigators. Dr. [redacted] and Mr. [redacted] will co-lead all project activities, with Dr. [redacted] leading the research and evaluation activities and Mr. [redacted] leading implementation activities. The Co-PIs will meet weekly by phone and monthly in-person during the first 6 months of the project (outside of planned activities) to confer on project progress and address any barriers to accomplishment of aims according to the proposed timeline. Any delays or significant barriers requiring a change in the project timeline will be addressed directly with Jen Brown at ARCC.

Table 1. Timeline and Milestones		Year 01		Year 02	
Task	Milestone	6	12	18	24
Readiness activities	Action steps for implementation finalized	+			
Review of measures	Measures finalized	+			
Adapt TXTXT	Procedures finalized		+		
Training Staff	All staff trained		+		
Implementation	Launch implementation		+	*	
Collect baseline data	Enroll 50 participants		+	*	
Collect Follow-up data	Collect 3, 6 month data from all participants		+	*	
Data analysis	Report of findings			+	*
Dissemination	Findings presented				+
+ indicated launch of that activity. * refers to task through the course of the project.					

Dr. [redacted] is Research Associate Professor at Northwestern University, Feinberg School of Medicine, and Department of Pediatrics and Associate Director of the Center for Gender, Sexuality and HIV Prevention at Lurie Children's Hospital, Division of Adolescent Medicine. She was a Co-Investigator on the TXTXT study and is now leading efforts to implement the TXTXT intervention in practice environments. In addition to this

proposed project with [redacted], Dr. [redacted] will serve as an advisor to the Coordinating Center for Technical Assistance of a current HRSA funded initiative to implement TXTXT in two healthcare organizations in New York City and Detroit (HRSA-18-053). Dr. [redacted] began her career in community service, working at [redacted] in Chicago (5 years) prior to beginning her academic career and then serving as Research Director at [redacted] (3 years) immediately prior to her current position at Lurie (7 years); thus, she has an intimate knowledge of the challenges faced by CBOs to adopt EBIs in practice. Throughout her academic career, she has been active in the development of primary and secondary HIV prevention interventions that have been based on community participatory approaches, resulting in five tested interventions described in the published literature.[1,15-18] She is currently Co-PI of a CDC funded project to test a homegrown HIV prevention intervention, developed at [redacted] for transgender women. Her prior experience in HIV community services, federally funded intervention trials, and translation of research to practice has prepared her well to lead this project with Mr. [redacted].

Mr. [redacted], MPH, is an Executive Director at [redacted]. In recent years, he has served as a co-investigator on an FDA pre-clinical of an HIV-syphilis assay along with Dr. [redacted], PhD, Professor Rutgers University, Robert Wood Johnson Medical School (2016). Mr. [redacted], also served as Co-PI for the Centers for Disease Control and Prevention awarded to the Illinois Department of Public Health (IDPH), Office of Health Protection HIV/AIDS Section, PS12-1201 Category C, funding to develop Demonstration Projects to Implement and Evaluate Innovative, High-Impact HIV Prevention Interventions and Strategies. At the crux of the on-going project, was the development and formative evaluation of the OASIS intervention. The Black OASIS Institute, was adapted locally, a homegrown HIV prevention intervention for HIV positive Black and Latino men and Transgender Persons who have sex with men (BLTMSM). Thus, Mr. [redacted] has the experience in both implementation of research and EBIs and is thus well-positioned to collaborate with Dr. [redacted] in this project.

D.2. Aim 1. Strengthen the community-research partnership between Lurie Children's and [redacted] using the community-based participatory research h (CBPR) partnership readiness model to structure activities. We recognize that our partnership to date has been driven more by research-related objectives, than practice-based implementation and thus, there is a need for re-focus on the practice environment and on sustainability of the partnership. We propose a series of partnership readiness activities, drawn from CBPR principles, in order to re-balance for this purpose.

D.2a. Readiness activities. In order to prepare for the implementation process, we will hold two 5-6 hour sessions to complete partnership readiness activities, structured by the community-research readiness toolkit, developed by the Center for Community Health Partnerships at the Medical University of South Carolina.[19] The sessions will be led by a professional facilitator and hosted at Lurie Children's. The toolkit was developed to operationalize the CBPR partnership readiness model, a heuristic model developed by Andrews and colleagues. In an application of the model to the CBPR, they found evidence to suggest that the sustainability of research-community collaboration is related to the partners' readiness for the various phases of the research process. Partnership readiness is defined as the degree to which the community-research partners, "fit" and have the "capacity" and "operations" necessary to plan, implement, evaluate and disseminate, will facilitate mutual growth, and will

TABLE 2. CBPR partnership readiness model

Tenants	Goodness of Fit	Capacity	Operations
Components	1. Shared values 2. Compatible climate 3. Mutual benefit 4. Commitment	1. Effective leadership 2. Inclusive membership 3. Complementary competencies 4. Adequate resources	1. Congruent goals 2. Transparent communication 3. Conflict resolution 4. Equal Power

positively influence the target community (see Table 2). Preparedness activities will be completed in two 5-6 hours sessions structured by tools provided in the readiness toolkit and including the following key themes: 1) Basic tenants of partnership; 2) Goodness of fit; 3) Capacity of partnership project; and 4) Partnership operations. Specific activities in the

toolkit facilitate joint discussion and planning in anticipation of a community-research partnership project. Dialogue related to goodness of fit focuses on shared values, compatibility of climate, mutual benefit and commitment. Capacity is promoted through discussion of effective leadership, inclusive membership, complementary competencies and adequacy of resources. Finally, operations' topics include congruency of goals, transparent communication, conflict resolution, and equal power sharing. Each theme is operationalized with a brief orientation, a set of reflective questions, rating questionnaires, and team discussion and development of action items. Prior to sessions, participants will be expected to complete reading materials for the planned session and the session facilitator will follow-up with participants to assure their completion. Attendees in these sessions include the Co-PIs, Project Coordinator and project partners. The milestone of this aim will be a full set of action steps for the implementation process.

D.3. Aim 2: Prepare for implementation of the TXTXT intervention at [redacted], by finalizing study measures for implementation process and outcomes, adapting the intervention to the local context at [redacted], and training staff.

C.3.a. Finalizing study measures. The implementation team will meet to discuss, debate, and finalize study implementation measures in a series of small group meetings to iteratively refine the evaluation objectives and related measures. The meetings will be held on site at [redacted] or via teleconference and will continue until the measures are completed, which is expected to take approximately four weeks. The proposed measures (subject to revision based on group process) are described below.

D.3.b. SMS text messaging platform. The TXTXT intervention consists of a set of daily, bi-directional and personalized text messages sent to clients to promote ART adherence. The set of messages includes an initial medication reminder, which is personalized by the client and timed to their dosage. The next message is a personalized follow-up message sent approximately 15 minutes later, which asks the client to indicate whether or not they took their medication (Yes, No); and the final message is an encouraging message to support the clients on-going adherence. The intervention approach is based on aspects of social cognitive theory (SCT; e.g., self-efficacy, motivation, sense of agency) and with features (personalization, encouragement) designed to be youth-friendly. The messages will be delivered to participants using a platform provided by Dimagi CommConnect (www.dimagi.com). Participants will create their own personalized reminder message that may be changed as requested throughout the intervention period. Some examples of personalization from our prior study include: "Have you taken your pills yet?" "Don't forget!" Participants will be asked to send a text message response indicating that have successfully taken their meds per schedule. An automated response system provides options for responding, including: 1) "Yes" or 2) "No." If the participant responds, "Yes" an affirmative and encouraging message will be sent in reply (e.g., "Great Job!"); a "No" response will trigger an acknowledging and encouraging message (e.g., "You can do it!"). We have designed 60 different youth specific messages that will be adapted as part of this project. Participants will use their own cell phones for receipt of messages. All text-related data will be securely stored by Dimagi per their privacy policy. Personalization in TXTXT reflects messages created by and for the participant themselves with consideration given to each person's need for privacy and confidentiality and timed to coincide with individual dosing schedule. To protect privacy and confidentiality, we will encourage participants to delete text messages after

taking medication, to use confidential messages that do not reveal HIV status or mention medications, and we will provide each participant with a fact sheet about cell phone confidentiality (e.g., passcode protecting phone).

Adapting the TXTXT intervention will include development of an intervention manual specific to the [redacted] context, adaptation of encouraging feedback text messages for the [redacted], and integration of the TXTXT intervention with local policies and procedures for related programs. The intervention manual will include specific instructions on how to run each visit that will form part of the project evaluation, as well as how to elicit and set up messages to be sent to participants. The feedback messages sent to participants were designed as a youth-centered supportive intervention. We will revise these messages in a set of 2-3 sessions with program staff for specificity to the environment at [redacted]. Finally, the TXTXT intervention will be integrated into the programming context at [redacted], including the supportive services environment. This includes additional interventions to promote adherence among dually diagnosed participants (Medisafe program), promotion of adherence among couples (SMART Couples) and Peer Support (group-level adherence intervention). For example, [redacted] focuses on supporting co-morbid mental health and substance use barriers faced by program participants. While the TXTXT intervention is expected to increase adherence for the majority of participants, some may not respond due to these psychosocial conditions. We expect to re-evaluate adherence at the 3-

month follow-up visit and for those who do not respond to the texts, we will refer them to additional supports offered by [redacted]. Procedures for this "warm hand-off" will need to be developed as part of our proposed project.
Training staff. Staff who will be implementing the intervention will be trained on the intervention manual, including specific instructions for entering SMS text message information into the texting platform; data collection, and on maintaining participant confidentiality. We will use the intervention manual as a training tool, coupled with specific instructions for integration with surrounding programs, drawn from our process described above. In addition, staff will be trained on the data collection process for each project visit and on participant confidentiality. We will train staff at [redacted] and partners to use a structured text message tailoring form to elicit message content and then set up automated messages in the Dimagi platform, i.e., set-up daily reminders according to the participants' dosing schedule and preferred message content. The training will be co-lead by the project Co-PIs.

D.4. Aim 3: Assess the implementation of TXTXT at [redacted] through evaluation of a pilot implementation trial. 4a. We will evaluate the implementation process and outcomes within [redacted] and among N=25 HIV positive participants. 4b. As an exploratory aim, we will also implement TXTXT among N=25 HIV negative participants who are taking pre-exposure prophylaxis (PrEP) medication to prevent HIV infection. We will begin implementation and evaluate implementation outcomes beginning in year 2. Participants will be recruited to begin receiving texts via the TXTXT platform and we will collect data from them in three project visits at baseline, 3-months and 6-months to assess their experience receiving the text messages and the impact of the text messages on their medication adherence (via self-report).

D.4.a. Implementation overview. To structure the implementation process, we will use the Consolidated Framework for Implementation Research (CFIR), a comprehensive implementation science framework which outlines a set of five domains[20]: 1) intervention characteristics (e.g., stakeholder perceptions, complexity), 2) inner setting (e.g., climate, leadership engagement), 3) outer settings (e.g., external policy and incentives), 4) individuals involved (e.g., knowledge, beliefs about the intervention), and 5) process of accomplishing the intervention (e.g., engaging appropriate individuals). As articulated by Keith and colleagues, by pre-specifying the factors that are known to influence the implementation process, the use of the CFIR framework increases the relevance of findings for implementation practice.[20] The CFIR is a flexible and adaptable framework that can be tailored to each implementation project, in this case, to implementation of the TXTXT implementation.

Keith and colleagues developed a "rapid cycle" evaluation process in which actionable findings are shared with stakeholders during implementation.[20] In each of the 5 CFIR domains, findings can lead to actions to address barriers and improve implementation. For example, if during the training portion of implementation, we find that the training manual is difficult to understand or follow, we will immediately revise it to improve implementation and uptake.

D. 5. Methods
Implementation trial. Beginning in year 2, staff of [redacted] will begin offering the TXTXT intervention to eligible participants. The implementation trial will run for approximately a 9-month period (enrollment, follow-up) in

which participants will be offered the intervention (initial 3-month period), "enrolled" in the program, and then followed for 6 months with collection of pre-post measures at baseline, 3 and 6 month follow-up, using self reported adherence and viral load suppression. We use these self-reported measures of adherence for the purposes of generalizability of on-going evaluation to practice. Participants will receive $25 at each visit for completion of self-reported measures (total = $75).

Eligibility. In this practice-based implementation trial, eligibility will be as open as possible to reflect real-world application, while maintaining applicability to the population to whom the intervention was originally targeted. Thus, eligibility criteria will include: 1) aged 18-29; 2) prescribed ART or PrEP and 3) a client of [redacted] or partner organizations.

D.5a. Data Collection
Implementation process outcomes. The initial objectives of the evaluation (subject to revision, based on group process) are to: 1) describe the changes being made by [redacted] to implement the TXTXT intervention; 2) describe the strategies used by case managers and others at the front-line of implementation to make those changes; 3) identify barriers and facilitators faced by those implementing the intervention. The tentative measures identified include those specific to elements of the Consolidated Framework for Implementation Research (CFIR), which are outlined as: 1) intervention, 2) inner setting, 3) outer settings, 4) individuals

involved, and 5) process of accomplishing the intervention.

We will collect descriptive data to evaluate the implementation process on an on-going basis, per the "rapid cycle" evaluation process developed by Keith and colleagues,[20] and consisting of closed ended questionnaire (Likert response scale) with items anchored to the CFIR evaluation domains as well as open ended items for free text responses. This questionnaire will be deployed monthly to front-line implementation staff in a web-based format using Qualtrics survey software under license to Lurie Children's. We will also use field diaries maintained by members of the study team to record day-to-day nuanced experiences with implementation and finally, post-implementation key informant interviews (N=5-8; not compensated) beginning 3-most after implementation with [redacted] staff and partners to identify key barriers and facilitators of the implementation process. Key informant interviews will be documented in written notes. In addition, Dr. [redacted] will maintain detailed noted on all of the CFIR constructs from the beginning of the funding period in year 1 to document and describe the evolution of the project through each stage of pre-implementation, implementation, and post-implementation.

Adherence outcomes. We will measure self-reported ART and PrEP medication adherence (past 30 days) using a visual analogue scale (VAS) of 0%-100% at baseline, 3-month and 6-month visits. The VAS correlates with unannounced pill counts, 3-day adherence recall, and viral load (r>=.7). We will also adapt for a 3-item set developed by Wilson et al., which has shown excellent reliability (α=.89)[21] as an additional measure of adherence. We will also measure viral load suppression via self-report.

Satisfaction. Participants will be asked the frequency of receipt of text messages, the degree to which they find the messages intrusive/bothersome, and whether the messages met their privacy expectations. We will use an adapted version of the 8-item Client Satisfaction Questionnaire [22] to measure satisfaction, (e.g., "How would you rate the quality of the text messaging intervention?"; "Did the text messaging intervention meet your expectations?"). We will also review reports of successful text sent/received to determine the level of exposure of participants to the intervention.

Human subjects. Lurie Children's will serve as the IRB of record for this portion of the project for collection of data from human subjects. In year 1, Dr. [redacted] will work with Mr. [redacted] to obtain a federalwide assurance (FWA) for the conduct of human subjects research at [redacted]. Dr. [redacted] has facilitated this process with two CBOs in prior projects, including most recently with [redacted] for a CDC funded project. All staff at [redacted] on this project will receive human subjects education, which will provide additional capacity building for future research collaborations with Lurie and other academic institutions.

D.6. Data Analysis. Implementation data from key informant interviews, detailed notes on the implementation process, and field notes will be analyzed with a directed content analysis, using the CFIR framework as structure for the coding process. Means, medians, and frequencies will be used to describe satisfaction data.

Pre-posttest differences in adherence outcomes will be compared using a paired t-test. This study is not powered for detection of efficacy as efficacy has been demonstrated in a prior RCT. The goal of analysis will be to describe the implementation process, including satisfaction, exposure and change in adherence as well as to describe the implementation process in detail via the qualitative data.

D.7. Potential limitations and how addressed. In this proposed community-research project, we anticipate that we could encounter unanticipated delays due to development of the text platform with Dimagi or barriers in recruitment of the target population. Our timeline includes a flexible initial year of planning and pre implementation activities in anticipation of technology or adaptation delays. If these delays go beyond the funded period, both organizations are prepared to support this initiative without funding until completion. In terms of recruitment of the target population for the implementation of the TXTXT intervention, if we encounter challenges in the recruitment process, staff of [redacted] will reach out to other community partners to increase recruitment. We have included funding for an outreach consultant in anticipation of this potential challenge as well.

D.7.a. Sustained research partnership/future research collaboration. Having sustained the current partnership between Lurie and [redacted] over the past 7 years, we feel confident that our partnership will continue in the future. Investigators at Lurie Children's are continuing to develop adherence interventions that may benefit BHC, including the "Stronger Together" intervention to improve engagement in care among sero

discordant male couples[23] and the "LifeSkills" intervention, focused on adherence to HIV prevention approaches among transgender women.[17] In addition, the development of the CBASI program at [redacted] provides focus and commitment to medication adherence issues at the organizational level for the foreseeable future. While biomedical HIV prevention and treatment approaches provide promise for "Getting to Zero" new HIV infections, which is the goal for the City of Chicago, adherence to these biomedical strategies continues to be the biggest challenge moving forward and provides opportunity for future continued collaboration.

D.7.b. Future research funding. Future research funding may come from several streams at NIH, including those focused on IS, PrEP and ART adherence interventions. For example, several institutes at NIH (e.g., NIMH, NIDA, NICHD) have participated in the recent "Dissemination and Implementation Research in Health" PAR in small mechanisms including the R21 (PAR-16-236) and R03 (PAR-16-237). Findings from this small implementation project may provide pilot data for future funding of an IS project in the areas of PrEP adherence support. Dr. [redacted] previously submitted an adaptation of the TXTXT for PrEP adherence to NIMH for funding (R21MH112446), which was well scored (Impact Score=30; percentile=16th). Although this proposal was ultimately not funded, the pilot work completed in this project could strengthen a resubmission application. A track record of collaboration with [redacted] for the TXTXT implementation would provide a foundation for future grant submissions in these areas.

D.7.c. Positive community impact. Both [redacted] and Lurie are committed to promoting adherence to HIV care through this initiative and anticipate a positive impact on the community. Very few adherence interventions have been developed for YMSM that are practical and scalable to practice. The TXTXT intervention is both practical and scalable. In the RCT, we found TXTXT to also have a relatively large effect size (OR>2.0) as well. All of these factors suggest that implementation to practice hold promise for this intervention. In addition, programmatic funding through the federal granting agencies, such as the Substance Abuse and Mental Health Services Administration (SAMHSA) may further magnify the community impact. For example, the TXTXT intervention could be incorporated into the Substance Abuse and HIV Prevention Navigator Program for Racial/Ethnic Minorities ages 13-24, which is a SAMHSA-funded initiative under which [redacted] will apply for funding. Identifying specific opportunities and pursuit of these opportunities will be a product of this collaboration.

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BUDGET CATEGORY	SUPPORT REQUESTED			SUPPORT IN-KIND	
	Community Co PI Funds	Academic Co-PI Funds	Total	Funding Source	Amount
Personnel					
Community Co-PI	-		$ -	[redacted]	$ 5,000
Academic Co-PI	-		$ -	Lurie Children's	$ 7,400
Project Coordinator	6,000		$ 6,000	[redacted]	$ 5,000
Community Peer Consultant	2,000		$ 2,000	Ryan White	$ 1,500
Academic Consultant			$ -		
			$ -		
Sub-total: Personnel	**8,000**	**-**	**$ 8,000**		**$ 18,900**
Non-Personnel					
Consultant Fees	6,450		$ 6,450	Lurie Children's	$ 14,000
Meetings	400		$ 400		
Equipment	375		$ 375	[redacted]	$ 150
Travel/Mileage	825		$ 825		
Supplies	200		$ 200	[redacted]	$ 300

Stipends	3,750		$ 3,750		
Sub-total: Non-Personnel	$ 12,000	$ -	$ 12,000		$ 14,450
TOTAL EXPENSES	*Total Requested*			*Total In-Kind*	
	$ 20,000	$ -	$ 20,000		$ 33,350

Budget Justification

Personnel

Academic Co-PI ($7,400 in-kind)

[redacted], PhD, MPH, is Research Associate Professor at Ann & Robert H. Lurie Children's Hospital of Chicago (Lurie Children's)/Northwestern University Feinberg School of Medicine, Department of Pediatrics, Division of Adolescent Medicine and Associate Director of the Center for Gender, Sexuality and HIV Prevention. She will devote 5% time to this project in-kind. She has 10% time covered by Lurie Children's for the development of new research initiatives of which she will devote half of that time to this project. She is well prepared to lead this study together with Mr. [redacted]. The study of primary and secondary prevention of HIV infection has been a key focus of her career as an early investigator. She has served as Co-Investigator on more than 10 NIH-funded studies of HIV-related prevention and care, including as Co-Investigator on the TXTXT study. She has a record of publications in the area of the basic HIV prevention research among high risk youth, as well a growing publication record reflecting the translation of this basic research into efficacious HIV-related interventions. Along with her colleagues, she has been at the forefront of HIV prevention research among high risk youth, identifying key social determinants of HIV risk and designing interventions to address these issues, together with members of the target population. The proposed study builds on and extends this research by seeking to implement the TXTXT intervention in practice and studying the implementation process. As an investigator who is relatively new to the field of implementation science, she will consult, as needed, with implementation science experts at the Center for AIDS Research (CFAR) at Northwestern University regarding the implementation science aspects of this project, where she is an affiliated member. Her role on this project will be to lead all research activities, including design of study measures, data collection and analysis in collaboration with the team at .

Community Co-PI ($5,000 In-kind)

Mr. [redacted], MPH, is the Executive Director at [redacted]. He will devote 5% time to this project in-kind from unrestricted funds. In recent years, he has served as a co-investigator on the FDA pre-clinical "Performance Evaluation of the DPP® HIV-Syphilis Assay in the Laboratory and at Point-of-Care Sites and Multiplex Screening Assays - Advancing targeted screening of co-morbidity via DPP® HIV-Syphilis Multiplex Rapid Test"; along with Dr. [redacted], Ph.D., Professor Rutgers University, Robert Wood Johnson Medical School (2016). Mr. [redacted], also served as Co-PI for the Centers for Disease Control and Prevention and the Illinois Department of Public Health (IDPH), Office of Health Protection HIV/AIDS Section, PS12-1201 Category C funding, to develop Demonstration Projects to Implement and Evaluate Innovative, High-Impact HIV Prevention Interventions and Strategies. A partnership of community-based organizations, collaborating in the development, implementation, and evaluation of a local homegrown intervention. At the crux of the on-going project, was the development and formative evaluation of the OASIS intervention. The Black OASIS Institute, was adapted from Many Men, Many Voices (3MV) locally, a homegrown HIV prevention intervention for HIV positive Black and Latino men and Transgender Women who have sex with men (BLTMSM). The adaptation integrated individual-, group-, and community-level

components into a 2½ day peer-led intensive weekend retreat. Sessions addressed: mental health (resolving internalized and external stigma), assertive communication, substance use and decision making, diagnosis acceptance and disclosure to past, current, and future sex and injection partners; relationship challenges, risk reduction, establishing a primary care home for life-long sexual health care, and informally promote community sexual health norms and treatment adherence norms within social networks. His role on this project will be to lead all implementation activities, including integration of the TXTXT intervention into practice, supervision of staff implementing the intervention and fiscal oversight for grant funds at [redacted].

Staff Coordinator $6,000 (requested; $5,000 in-kind)

[redacted], Is a Doctor of Medicine candidate in Pediatrics**,** with an interest in community medicine that focuses directly on prevention of disease and promotion of health. He is taking time off his medical preparation to work directly in the community with [redacted]. He will allocate 15% time to this project (6 hours/week). Mr. [redacted], is devoted to critical medical anthropology to understand the social determinants of healthcare by tackling the negative influences of urban and rural environments which may prevent access and exacerbate conditions that lead to health inequities of

LGBTQ youth experiencing health disparities. Mr. [redacted], will serve as project coordinator on the TXXT study and oversee implementation and liaise with Dr. [redacted] for research activities.

Digital Navigator and Community Peer Consultant ($2,000 requested; $1,500 in-kind)
[redacted], is a Digital Community Peer Consultant. Mr. [redacted] will serve as community advisor to the study for participant digital engagement. He will assist with participant outreach, recruitment and engagement via Facebook and other social media to assure active participation.

Consultant Fees $6,450.00 (Requested)
The $6,540 to the text message vendor, Diamgi, a technology company with a ten-year history of designing, building and launching digital systems. Dimagi has worked with Lurie Children's to adapt the TXTXT platform, which is HIPAA compliant, for use in this project. The Dimagi cost is comprised of two components as follows: Dimagi Pro Software Plan: This includes a 12 month subscription fee to the PRO CommCare Hosting Edition (year 2 implementation; $500 x 12 months=$6,000). This includes access to CommCare features included in the PRO plan up to 250 mobile users. SMS Costs: Dimagi charges $.01 for each SMS sent through the system. On top of that, the SMS gateway used by the program will charge an additional $.01 for each SMS. The total costs of SMS for the program will therefor vary depending on the total number of SMS sent. We estimate $540 for the cost of these texts. An additional $14,000 will be contributed by Lurie Children's in-kind to refine and adapt the text messaging platform for this project.

Meetings $400.00 (Requested)
We plan to provide light snacks and nutritional supplements (cookies, fruit, juice, sandwiches) at all the meetings. We plan on holding two session meetings in order to prepare for the implementation process, we will hold two 5-6 hours sessions to complete partnership readiness activities, structured by the community-research readiness toolkit, developed by the Center for Community Health Partnerships at the Medical University of South Carolina. The sessions will be led by a professional facilitator and hosted at Lurie Children's. The toolkit was developed to operationalize the CBPR partnership readiness model, a heuristic model developed by Andrews and colleagues. Budgeting $400.00 to provide snacks will give us approximately $33.00 for each meeting which will be sufficient to cover 12 attendees per two sessions.

Equipment $375.00 (Requested; $150 in-kind)
We will need 1 laptop to support the coordinator and peer consultant coordinating the TXTX Study, estimated to cost $525.

Supplies $200.00 (Requested; $300 in-kind)
We will need binders, plastic ware for group meetings, copy paper, printer toner, pens and lockboxes for confidential documentation, estimated to cost a total of $500 over the grant period.

Travel Mileage $825.00 (Requested)
Transportation is a key factor to address participant barriers often times impede participation of low income individual engagement. We anticipate 50 persons needing assistance with round trip transportation CTA Ventra passes each visit for completion of self-reported measures at three intervals. Participants will also be asked to attend meetings with the coordinator to address barriers to implementation. We would therefore like to budget for at least 137 passes at $5.50 per round trip ride passes. [137 x $5.50 = $825.00 over a six month period].

Stipends $3,750.00 (Requested)
We plan to offer stipends ($25.00/evaluation visit). We expect to recruit 50 persons to voluntarily participate in the study. [50 persons x 3 evaluation visits x $25 = $3,750.00]

Link to PDF of 2 additional applications

Page 1 Partnership Development Round 4/2011

Page 12 CBPR Implementation Round 3/2010 (now called Research Pilot)