MCKNIGHT BRAIN RESEARCH FOUNDATION (MBRF) Meeting of the Education Committee of the Board of Trustees

Tuesday, July 11, 2023 5:00 pm – 6:00 pm ET

https://zoom.us/j/92017815568?pwd=d2tGdkwvaHZscDFDV3FLSWtqUUIZdz09

Committee Memb	ers:	Dr. John Brady, Chair; Dr. Mike Dockery, MBRF Chair; Dr. Patr Brangman	icia Boyle; Dr. Sharon
Also Attending:		Dr. Lee Dockery, MBRF Chair Emeritus; Dr. Angelika Schlanger Patmintra; Dr. Kate Lorig, CEO, SMRC; Dr. Basia Balza, Univers	
Not in Attendance	2:	Dr. Allison Brashear; Dr. Roy Hamilton	
		<u>AGENDA</u>	
5:00 pm ET	1.	Call to Order/ Welcome/ Roll Call	Dr. Brady
ACTION		a. Minutes from January 25, 2023 Meeting	
		b. Updated Committee Activity Timeline	
5:05pm	2.	Proposals for Brain Health Initiative for Consumers	Dr. Brady
		a. Introduction and Welcome to SMRC and UW	Dr. Schlanger
		b. Presentation of Proposals	
		• SMRC	Dr. Lorig
		• UW	Dr. Balza
ACTION		Question and Answer Session	Du Dundu
ACTION 5:40pm		c. Discussion of proposals	Dr. Brady
от т ор	3.	Updates on Outreach Efforts related to Brain Health	Dr. Schlanger
		a. Concept Paper Submitted by GSA	· ·

Dr. Brady

6:00 pm ET

ACTION

4. Adjourn

MINUTES MCKNIGHT BRAIN RESEARCH FOUNDATION (MBRF) EDUCATION COMMITTEE CONFERENCE CALL January 25, 2023

Draft for Committee Approval

The Education Committee of the MBRF was called to order at 2:00 pm EST on January 25, 2023, by Dr. John Brady.

The following members were present:

Dr. John Brady, Education Committee Chair

Dr. Mike Dockery, MBRF Chair

Dr. Allison Brashear, Trustee

Dr. Richard Isaacson, Trustee

The following members were absent:

Dr. Patricia Boyle, Trustee

Others attending:

Dr. Lee Dockery, Chair Emeritus

Ms. Melanie Cianciotto, Corporate Trustee

Dr. Angelika Schlanger, Executive Director

Ms. Valerie Patmintra, Senior Communications Advisor

Mr. John Beilenson, CEO of SCP

1. Call to Order

Dr. Brady welcomed the members of the committee to the call.

2. Minutes of the October 17, 2022, Meeting

The minutes of the March 13, 2022, Education Committee Meeting (Attachment 1) were reviewed and approved with no changes.

Action Item 1: The minutes of the March 13, 2022, Research Committee Meeting were approved (Attachment 1).

3. Updated Activity Timeline

The committee reviewed the updated Activity Timeline (Attachment 2). Dr. Brady highlighted that the MBRF is awaiting an updated agenda for the May 2023 Inter-Institutional meeting. He also highlighted that the MBRF Finance Committee re-approved a budget for the ABF Scholars dinner at the 2023 AAN conference. Finally, he shared the return of the Annual Luttge Lecture on February 23, 2023, at 12PM EST, which will feature Dr. Joshua Gordon, the Director of the National Institute of Mental Health.

4. Primary Care Provider Initiative Update and Discussion

Dr. Brady introduced Mr. John Beilenson, CEO of SCP, to give a presentation on the strategies presented in the scoping document developed by SCP, "Grant Options for a McKnight Brain Research Foundation for an Education Initiative" (Attachment 3).

John and his team have been working over the past several months on a landscape analysis to help the Foundation determine the best approach to launching an initiative to empower and educate primary care providers on the topic of cognitive aging. His initial findings from the landscape analysis were shared with the committee in December, and today he is presenting his team's initial recommendations of how the education initiative could be rolled out.

His recommendations are based on the MBRF's designation of four key themes of interest: 1. partnerships are needed to be successful; 2. link cognitive aging education to a larger evidence-based wellness or disease-prevention initiative; 3. enhance knowledge of PCPs around cognitive aging; and 4. explore the best use of cognitive assessments. SCP felt that the interest and alignment of the MBRF advisory group was focused on the first three themes, which they developed into the following proposed recommendations outlined in the scoping document:

- 1. Partner with a public health/community health education initiative to infuse cognitive aging/brain health into its offerings. There is already a considerable amount of work being done in health education and prevention. SCP suggests working with these organizations to infuse cognitive aging into these existing initiatives and to also help broaden dissemination.
- 2. Bolster public education aspects of existing evidence-based interventions focused on cognitive aging and dementia in primary care. SCP has found that the most emphasis and focus on brain health programs in primary care are on cognitive issues, not cognitive health in general. SCP recommendations further exploring the existing models supported by evidence and enhance or expand the community referral and education component of these models. There are already many of these materials out there, so we need to build a case and rationale for the PCPs to use this more proactively.
- 3. Frame and launch a public information campaign for PCPs focused on cognitive aging, lifestyle change, and dementia prevention. SCP recommends finding a set of strong national dissemination partners to ensure we have the channels to get the word out about cognitive aging and connect this to existing or new Continuing Education (CE) programs on this topic. We would leverage the existing capacity of other well-established national organizations, such as The American Heart Association's (AHA) Essential 8 program. Also, Us Against Alzheimer's is already developing CE and Continuing Medical Education (CME) programs on this topic, another opportunity for patnership. A third potential partner with a broad distribution channel is the AARP's Global Council on Brain Health. The goal of these efforts would be to change the knowledge base and behaviors of PCPs.

Dr. John Brady thanked SCP for the great work they have done these past few months. He opened the discussion with the group to share their questions and feedback on the process and the recommendations with Mr. Beilenson.

Dr. Mike Dockery mentioned the importance of distinguishing the MBRF's initiatives and mission from that of Alzheimer's Disease (AD) groups. He also thought the recommendations would be looking to see what curriculum is already available around brain health and cognitive aging, identify gaps the MBRF could fill, or find ways to leverage existing resources to avoid recreating the wheel. He questioned why SCP is emphasizing partnerships so heavily in its recommendations.

Mr. Beilenson responded that MBRF currently lacks the dissemination capacity to engage large numbers of people. Therefore partnering with organizations that have larger resources and established national distribution channels would be the most effective way to proceed.

Dr. Isaacson said that partnering with an AD organization is not a problem as long as we frame it so we can marry together the disease as well as the prevention side. There would need to be flexibility on behalf of both organizations to meet in the middle.

Dr. Lee Dockery asked how such messaging would be different from the broad distribution of existing content on brain health by organizations like the CDC and AARP's Global Council on Brain Health. He also raised concerns around the MBRF's messages being absorbed by an AD-focused organization and how to distinguish our messaging to maintain autonomy. He also mentioned it may benefit to partner with CMS or supplemental insurance and to take into account the various resources on cognitive health that are produced by the NIA, to ensure a complementary strategy to what already exists. He reminded the group that we should be focused on healthcare providers and not just physicians.

Mr. Beilenson agreed there are a lot of informational resources on brain health for consumers, which is why SCP's recommendations are focused more on healthcare. He suggested we should connect MRBF's messaging to clinical practices as best we can.

Allison echoed Lee's concerns and asked what success would look like - is it increasing awareness, standing up a pilot project, or increasing NIH funding? What are the specific outcomes? She affirmed we should not get into the AD space, as there are already many organizations occupying that field.

Mr. Beilenson highlighted that outcomes are listed in the document for each focus area, for example creating new cognitive aging modules for PCP education. He posed the following question: what is most important to the MBRF - to promote the name/brand of MBRF - or to promote the vision and idea? He shared that SCP's recommendation would be the latter, but suggested that the chosen initiative could be shaped in either direction.

Dr. Lee Dockery responded that the brand and the topic of cognitive aging are connected and that the MBRF is the only foundation bringing awareness to cognitive aging outside of Alzheimer's. Mr. Beilenson concurred and highlighted that when creating partnerships with other organizations, there is

also a question of whose name is "on top" and that there is a tradeoff between the ability to get the word out broadly and the ability to get our brand out front and center.

Dr. Isaacson said that MBRF would need to invest significant funds in a multi-year project to build out a presence or pay an education CME company or partner. Building content without expanding the reach is not worth it. The MBRF's brand recognition could take a hit in terms of partnering, but he questioned how we would be able to meet the goal otherwise. He asked Mr. Beilenson to advise on this trade-off.

Mr. Beilenson explained that nonprofits and foundations have different challenges in raising brand awareness. Nonprofits have to raise their own dollars - if they don't have visibility, they will not be able to compete for grants and donations. Typically, foundations that are built on endowments have more flexibility to invest in projects that advance their mission even when they do not get the full credit for doing so. For example, funding a research project at a university may create huge advancements or "wins" for the mission of the foundation, but may not bring a huge increase in brand recognition. Still, the brand would not be invisible, and there are ways to make sure the foundation's name is connected and mentioned in bylines, websites, etc. However, he concurred that building the MBRF brand is important to enhance our thought leadership and ability to partner via our reputation. This would enable MBRF to broaden its impact and develop synergies that go beyond just the dollar investment.

Dr. Brady asked if there were further questions, and seeing none, he concluded the discussion with Mr. Beilenson and thanked him for his presentation. Dr. Brady then opened up the discussion to the group with the following questions: Was there anything missing or surprising? Any concerns you have?

Dr. Mike Dockery shared he thought this would be more of a game plan that we could follow to get the result we would be anticipating and to identify specific groups or a spokesperson who could help advance our agenda. Dr. Brashear concurred and shared disappointment that the content was not targeted to a specific endgame and thought that this scoping document would present a different angle specifically around how to prevent age-related decline in the brain.

Dr. Brady asked Dr. Schlanger to reflect on the process or the feedback that's been shared. She shared additional remarks by Mr. Beilenson that highlight the crux of the challenge, from SCP's perspective – that there is already a lot of information available for consumers and PCPs, and that the main issue is not creating more content, but developing the demand, context, and rationale for PCPs to use the content to counsel their patients.

Dr. Lee Dockery, shared that he concurs with Allison that we cannot boil the ocean. When we started this project, we were looking to influence PCP practice through ongoing and earlier assessment of cognition and patient counseling. The research study confirmed that PCPs face challenges in terms of having enough time with patients, lack of tools, and the fact that reimbursement rates are linked to disease states rather than health-maintenance. A positive outcome of the SCP study is reaffirming that there is indeed a need to influence practice behavior. Though SCP has offered opportunities to spread information through another AD-focused organization's distribution channels, Dr. Lee Dockery believes this will not solve the issues.

Dr. Isaacson shared he gets contacted frequently by healthcare providers across the country who want to counsel their patients on brain health and cognitive aging, but they do not know how to get reimbursed to make this viable. He offers a course and monthly meetings on this topic, but they always get to the same conclusion which is that there are no diagnostic codes or reimbursement codes to do cognitive assessments for a healthy individual; PCPS only get reimbursed on a cognitive screen with a sick treatment diagnosis. He mentioned that the billing codes are a root cause of the PCPs not being able to provide guidance and assessment from a wellness standpoint. He concurred with Lee that this is a valuable conclusion, and what we may need to advance is advocacy, not education.

Dr. Brady shared that PCPs can always find the time to counsel and assess, it has to do with prioritizing. However, if the financial model does not enable reimbursement for the assessments, then you won't have PCPs buying into this. Dr. Isaacson shared that he's tried to help other brain health clinics set up a viable model, but it always boils down to the money, and philanthropy keeps having to pay for it because insurance companies won't.

Dr. Mike Dockery asked Dr. Brady to share his feedback on the scoping document. Dr. Brady shared that we learned a lot from this process but didn't feel that the scoping document hit on things that we should move forward. The information felt overwhelming and the recommendations, like community health programs, will take a lot of work. He is still uncertain how to move forward.

Dr. Schlanger shared that the presentation that SCP gave in December had several slides on needs related to advocacy (e.g. establishing clearer guidelines on cognitive assessments during the annual wellness visit), as well as reimbursement codes and the business side of doing cognitive assessments, reaffirming the importance of these topics. Additionally, while the scoping document is very high level, once the MBRF selects its chosen direction, we could leverage internal MBRF resources or work with SCP or another group to flesh out a strategic plan that would have precise action steps, timelines, and deliverables.

Dr. Isaacson responded that given our broken preventative healthcare system, maybe what we need to do is to raise awareness of the problem to through advocacy. We have learned in this process that PCPs and patients want the information, but we have this larger issue preventing us from getting there.

Dr. Lee Dockery asked Dr. Brady what percent of patients come in for annual wellness/health maintenance visit. JB answered that his practice's goal is 60% for Medicare-eligible patients and 30% for younger patients. Dr. Brady also answered around waiting times, which is about 3 weeks to several months, depending on the practice.

Dr. Mike Dockery shared that the opioid-epidemic practice guideline since January 1, 2023 is to screen for depression, even though his practice cannot treat depression. There have been several groups that have been successful in getting things on the national radar.

Dr. John Brady summed up that maybe we need to go back to SCP and let them know we are thinking more about how to do the advocacy part to get the message out that preventative care needs to be reimbursed. Dr. Dockery suggested we should not lose sight of the information that is in the landscape

analysis, and what we can leverage from that document. Dr. Brady asked the group to email him and Dr. Schlanger their top 3-4 takeaways. Dr. Schlanger affirmed she will ask SCP to develop a 4th path around advocacy, so the outcomes and timelines could be compared to the other items.

6. Updates on Primary Care Provider Section of Web site

Dr. Schlanger updated the group that we are doing a refresh of the web site. Within the PCP section of the web site, we are seeking to have a new Patient Resources page that would serve as a single hub or repository for PCPs seeking cognitive aging resources and information for their patients. We will share the web site updates at the Trustees meeting, and at a future time, the education committee will review what items could be included in this section, such as the Cognitive Aging and Brain Health Brochures.

6. Adjourn

Dr. Brady asked if there was any further discussion. Hearing none, he called for adjournment of the meeting at 3:05 p.m. EST.

Respectfully Submitted,

Angelika Schlanger Executive Director

Education Committee Activity Timeline For the Years 2019 – 2023

Updated June 2023

Duty (from Committee Charter)	Activity/Action	Outcome	Date	Comments
"shall develop information and resources (for the public and scientific community) on prevalence and impact of age-related cognitive decline and memory loss	Work toward alignment of messages across the MBIs and MBRF Make substantive judgments on content and quality of educational content/statements developed for or posted on the website	Key Messages Were Approved and Distributed in Spring 2019	July 1 – ONGOING ONGOING Review of Topics and Content for Primary Care Physician (PCP) pages on website February 2021	The Education Committee reviews content before it is posted on website, published, or included in print materials or slide presentations, ensuring consistency with key messages. The committee reviews for accuracy, soundness, and alignment with the MBRF mission and current scientific understanding and clinical practice. (The Research Committee also reviews content before making public.)
	A top priority for the committee and MBRF, as approved by the Trustees, is to identify and/or develop educational content for primary care physicians and to oversee the ongoing posting of additional information	The committee approved an outline of resources for the PCP Area on McKnightBrain.org The committee approved drafting content for the PCP area of the website based on the approved outline navigation of the section	DONE June 30, 2020 DONE September/ October/November	

Duty (from Committee Charter)	Activity/Action	Outcome	Date	Comments
		The committee reviewed proposed navigation and drafted content for the Primary Care Physician (PCP) pages of the website	DONE February 2021	
		Content will be revised and edited to include feedback from the committee and used to build out a mock-up of the PCP section	DONE February – March 2021	
		An Update to the Trustees will be provided	DONE April 30, 2021	
		The PCP section will be shared with suggested primary care physicians for feedback and suggestions.	Winter/Spring 2022	
		Dr. John Brady, Chair of the Education Committee will be instrumental in helping to develop strategy and content	ONGOING	
And" assist those living with age-related cognitive decline and memory loss"	Website content developed for individuals, families and caregivers of those with agerelated cognitive decline and memory loss	Add links to approved articles as appropriate but development of content is on hold until PCP content is identified and developed.	Winter/Spring 2022	
Inform "how to better maintain brain health"	Website content developed for individuals on how to protect, maintain brain health	Add links to approved publications and articles	July 1 – ONGOING	Committee Reviews before Posting

"shall review all educational materials:	Brochure copy in development to raise awareness and promote the MBIs and MBRF to individuals, partners, donors	Review of Brochure was conducted and committee concurs with suggestions by Communications Committee	DONE Posted on website January 2021	
"Identify educational opportunities and implement activitiesto encourage MBIsinspire	12 th Annual Inter-institutional Meeting	2020 Meeting was canceled 2021 Meeting will be virtual	April 28 & 29 2021	DONE
commitment and shared vision"	13 th Annual Inter-institutional at UA	Meeting was in-person	Mar 23-25, 2022	
	14 th Annual Inter-Institutional Meeting, UAB	Meeting was in-person	May 3-5, 2023	
	McKnight Scholars Will be invited to next Inter- institutional Meeting	Develop Feature on McKnight Scholars on McKnightBrain.org		Will help promote scholarship and engage scholars
	McKnight Scholars Dinner at AAN	2020 Toronto, AAN Meeting was canceled 2021 Virtual AAN Meeting	April 17 – 22, 2021	Held over - MBRF approved funding of \$4,000 to cover travel, hotel for the night, dinner, UM staff travel
		Took place at the April 2023 AAN Meeting		Approved by full board at February 2023 meeting
	William G. Luttge Annual Lectureship in Neuroscience at the University of Florida	Annual Lectureship by research scientist of National or International prestige in the field of neurosciences	Held in March/April each year in conjunction with Brain Awareness week. 7 th lectureship was by Dr. George Koop March 11, 2019 2020 Lecture was canceled.	Annual Lectureship established honoring the Founding Director of the Evelyn F. and William L. McKnight Brain Institute at the University of Florida Events as part of the William G. Luttge Lecture

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			2021 Lecture to be	2021 to become a Lecture
			held in Fall 2021	Series.
				DONE
			2022 Virtual Lectures	BOILE
			January 13 - Dr.	
			Alexis Stranahan,	
			PhD, UF	
			Feb 24 – Dr. Perla	
			Moreno Castilla,	
			PhD, "Rising Star"	
			Luttge Lecturer, NIA	
			March 3 – Dr. Dan	
			Nicholson, PhD, Rush	
			March 31 – Dr. Kirk	
			Erickson, PhD,	
			University of	
			Pittsburgh	
			rittsburgii	DONE
			2023 Lecture:	DOINE
			February 23 rd – Dr.	
			Joshua A. Gordon,	
			MD, PhD, Director,	
			National Institute of	
			Mental Health	
			(NIMH)	
"work to elevate the				
importance of age-	IOM Study	"Public Health Dimensions of	DONE	Study funded by MBRF and
related cognitive decline		Cognitive Health" was released by	April 14, 2015	federal agencies (NIA,
and memory loss on the		the IOM (see attached document)		CDC, NINDS, HHS), AARP,
national agenda(work				Retirement Research
toward) greater				Foundation
investment in research				
and education by federal		Working Group formed under the	CURRENTLY NOT	
health agencies"		lead of Dr. Molly Wagster	MEETING	
		, ,		

	impleme	as initiated and ented several of the IOM nendations.	ONGOING	
	with ION	Dockery was in contact M (now Academy of e) about issuing a report ress	October 23, 2019 NOT TO BE PURSUED	This would be unusual for the Academy of Medicine to do per Dr. Molly Wagster.
"work to elevate the importance of age-related cognitive decline and memory loss on the national agenda"	of AAN, that the related of	h Sacco, former President recommended to AAN y support adding age- cognitive decline and y loss to curricula for ments	July 11, 2019	Letters were sent from AAN to MBRF, American Board of Psychiatry and Neurology, and ACGME
	Dockery Gordon Educatio Jaffar Kh Educatio	ert Wah and Dr. Lee spoke by phone with Dr. Smith, Chair, AAN on Committee, and Dr. nan, Chair, AAN Graduate on Subcommittee, to collaborative steps	August 8, 2019	
	Drs. Smi Malloy r	up communication with ith and Kahn and Kathy re: schedule for review of requirements by ACGME	DONE September 16, 2019	On distribution list for ACGME e-Communication with schedule for review of special requirements
			June 2020 NOT TO BE PURSUED	Committee feels they've done all they can do at this time.

	1	
Discuss strategy to achieve MBRF Education goals to reach Primary Care Physicians and the Public. Discuss benefits of additional staffing and advisory groups working with the MBRF		Done March 13, 2022
Identify and hire consultant for feasibility assessment and scoping document assessing the educational needs and opportunities with PCPs regarding cognitive decline.	Consultant (SCP) was selected by the Trustees on September 20, 2022 after a thorough vetting process, and the project kicked off on Oct 10, 2022 with a meeting with a group of Trustees. The study and final report will be completed February, 2023.	October 10, 2022
	SCP gave a progress update to Trustees at their Board Meeting.	October 27, 2022
	Another update to Trustees took place on Dec 21, 2022.	Dec 21, 2022.
	SCP presented the draft scoping document to the Education Committee. The committee provided feedback to SCP. SCP is working to revise the document with a final version presented before the Feb 16, 2023 BoT meeting.	Jan 25th, 2023
	SCP presented the final report at the February 16, 2023 Board of Trustees meeting.	February 16, 2023
	A consultant may be needed to implement the Education	TBD

	Initiative. If so, the Education Committee will make a recommendation to the Trustees on seeking and engaging a firm to implement the initiative		
Education Outreach Initiative to Primary Care Providers and Consumers	Key Messages document was completed for both PCPs and consumers, with input from Trustees	March 2023	
	Outreach to national organizations has taken place to recommended and aligned organizations to explore potential synergies and partnerships; outreach began in March 2023.	Ongoing	
	SMRC and UW submitted proposals to advance the MRBF's Brain health initiative. GSA submitted a concept paper.	June 2023	

Overview of Education Initiative Proposals

Prepared by Angelika Schlanger, PhD

July11, 2023 Education Committee Meeting

Background

Following a discussion and vote by the trustees at the May 3, 2023, the Executive Director invited SMRC (Self-Management Resource Center) to submit a proposal to develop a community- and evidence-based brain health curriculum for consumers to advance the strategic goals of the Foundation (Strategy #1 approved in the MBRF February Trustees meeting). SMRC has enthusiastically responded to this invitation, and engaged an evaluation partner, the University of Washington The combined request would also enable the MBRF to strategically advance Strategy #2 – which is to develop educational resources and tools for PCPs – as the curriculum may provide multiple opportunities for integration with primary care, which are outlined below.

Included in the Education Committee's Packet are two proposals related to the education initiative:

1) SMRC is a small, mission-driven for-profit organization created by the founders of the Stanford Chronic Disease Management suite of programs. Their proposal, submitted by Kate Lorig (Partner and Founder), requests \$89,000 over four years to develop, train, pilot, help evaluate an evidence-based brain health curriculum. Once developed and piloted, SMRC will offer the brain health curriculum along with its other 6 programs to its 1,000 existing partners and future partners, including non-profit organizations, state agencies, health departments, and healthcare systems.

SMRC's business model – which offers training and highly affordable licenses to non-profit and public agencies that deliver the curriculum – provides long-term sustainability to enable this work in perpetuity. Kate is confident there will be great interest by partner organizations and participants. SMRC's partners include the National Council on Aging, Veterans Administration (VA), State of New Mexico, American Diabetes Association, the National Council on Aging, YMCAs, Urban Leagues, and many more, including entities outside of the United States.

2) The University of Washington (UW) is SMRC's selected evaluation partner. Their proposal was submitted by Principal Investigator, Basia Belza, a highly qualified and experienced nurse-scientist who has been funded by the CDC and other leading organizations to evaluate community-based wellness programs, particularly those serving older adults. The request for \$304,429 over a period of up to three years is to fund an independent evaluation that will meet the criteria outlined by the Administration for Community Living (ACL) for an "evidence-based" program. This includes publishing the outcomes in a peer-reviewed journal. In addition to meeting this gold standard definition, ACL approval enables public dollars through the Older American Act (OAA) Title III-D funds to be used to support the implementation of the program in communities across the country.

Although it was initially thought that SMRC would submit a single proposal to include the UW as a subcontractor, SMRC has requested that the MBRF approve and make two separate grants – one to SMRC and one to UW. SMRC is unable to manage UW as a sub-contractor due to its lean staffing structure.

Track Record

Previously under the auspices of the Stanford Patient Education Research Center, Kate and her team have a long track record of developing education programs at the request and support of private and public entities. Other

funders have invested in the development of the Self-Management Curricula and evaluation research and these programs continue to be offered widely today (decades later) with recognition from various federal agencies.

For example, the Robert Wood Johnson Foundation helped fund the development of the Positive Self-Management Program [HIV], which was launched in 1997 and continues to be offered today. This program is considered an evidence-based program by the Administration for Community Living (ACL). The Archstone Foundation and the American Diabetes Association (ADA) supported the development of the Diabetes Self-Management Program in the early 2000s – this successful program has been accepted as part of the ADA's diabetes education programs eligible for Medicare reimbursement and as an evidence-based program by the ACL. In 2010, the U.S. Veterans Administration approved the Center to develop a curriculum to support Caregivers. The program, which also received funding from the Archstone Foundation, is currently used by the V.A. caregiving programs and is eligible for Older Americans Act Funding. In 2012, the Center developed a Cancer Thriving and Surviving program which continues to be offered and is also considered an evidenced-based program by the ACL.

MBRF Advisory Group

As SMRC staff are not experts in brain health, it will be important to have MBRF Trustees, MBI partners, and/or other designees engaged in providing direction over the curriculum content and the key outcomes being evaluated through the study. SMRC will flesh out the "Key Messages for Consumers" provided by the MBRF and leverage existing evidence-based content in their curricula that is aligned with those messages (i.e. healthy eating, sleep, managing stress, etc.). Members may include the Education committee and other interested trustees of the MBRF, MBI representatives who have experience in community interventions (to be determined in consultation with each MBI director), and external partners. The membership, timing and format of these interactions can be developed during the project period, if the grant is approved.

Licensing Structure

SMRC offers very affordable 3-year licenses that amount to about \$28 per workshop (most workshops consist of 6 sessions), which includes training for the facilitators. They have a transparent licensing structure explained here and a sample agreement that is posted here. Angelika has asked whether licensing fees could be waived for the McKnight Brain Institutes, should they wish to use this curriculum, and they are open to working out a possible arrangement.

Ownership and Intellectual Property

According to this model, SMRC would own the intellectual property rights to the curriculum. If the grant is approved, the MBRF can develop a contract with the SMRC that details their obligation to maintain, disseminate, update, and continuously promote the curriculum in perpetuity. SMRC's ownership of this curriculum may be viewed similarly to MBRF's funding of scientific research, where the data and outcomes of the research are owned by the lead investigators, and not the Foundation. If at any point SMRC decides to stop offering the program, ownership of the brain health content developed for this curriculum will revert to the MBRF.

Revenue Sharing Possibility

There may be an option for the SMRC to share revenue with the MBRF if the licenses reach a certain threshold. The details of this will need to be worked out with SMRC and assessed by legal counsel.

Legal/Tax Due Diligence & Compliance

In consulting with legal counsel at Akerman, it was advised that SMRC's proposal will not present any issues with tax or legal compliance and can count as qualifying distributions, a question that was posed due to SMRC being a for-profit: "Assuming that the Board is in agreement to the budget, the proposal looks to be reasonable and in line with the charitable focus of the Foundation... Since these expenditures fall within the charitable purpose of the foundation, as direct program operational expenses, these expenditures should qualify as qualifying distributions." The grant to UW would also be considered a qualifying distribution.

The licensing agreement used with the nonprofits was shared with legal counsel who confirmed there is not a compliance issue with the MBRF funding this model. The revenue-sharing opportunity was also discussed with legal counsel who confirmed that this should not affect the foundation's tax status, and that it can be considered "program investment income."

Grant Agreements/Contracts

If approved by the Trustees, it is proposed that we will engage legal counsel to review the contracts. If possible, we will ask both SMRC and UW to develop a draft agreement that will incorporate the proposals that were approved, inclusive of budgets, timelines, and outcomes. We will work with counsel to incorporate reporting requirements to the foundation; outline the responsibilities of the two entities to each other within each of these agreements (or through a 3rd agreement); and to address the question of ownership and responsibility to sustain the program in the SMRC contract. We will incorporate all guidance from legal counsel and address any specific items requested by the Trustees. This process has been discussed with legal counsel and these various requests can be accommodated.

Evaluating the Investment

Based on SCP's landscape analysis, scoping document, and my own research and experience, SMRC appears to present the strongest combination of broad reach, proven impact, expertise, strategic partnerships, track record, and sustainability, for developing and disseminating a brain health curriculum that can improve knowledge, behaviors, and health outcomes around brain health. For over 40 years, Kate Lorig and colleagues (several of whom are part of the SMRC team) have been developing and disseminating health education programs that have acquired a strong reputation and national renown in this space – recognized and approved by federal agencies for public funding. If approved, the combined budget of \$393,429 over four years will enable the MBRF to tap into a well-developed and effective model of community-based health education that will be financially sustained by SMRC's licensing structure, without the need for further investment by the MBRF.

The advantage of funding SMRC is that it has the infrastructure to train, develop, update, sustain, and disseminate evidenced-based curricula, which the MBRF can leverage through this partnership. The MBRF would benefit from an affiliation with a leading and trusted provider and have its visibility increased with its logo included on program-related materials that are distributed to over 1,000 (current) partners and the program participants. Over thirty years of published research supporting the effectiveness of the programs developed to date (in Spanish and English, in person and online) can be found here. Finally, we are exploring extensions into primary care. For example, PCPs could refer patients to a local brain health workshop, can host trainings at their facilities or nearby, and can train their own staff to give these workshops to patients and families, etc.

As with any investment, there are some risks to consider. This includes a chance that the evaluation does not demonstrate the effectiveness of the program. This risk will be minimized by ensuring the approval of the

curriculum by the MBRF Advisory group of experts, and leveraging SMRC's existing content and program structure, which have been proven effective by dozens of studies. Another risk may be that at some future point SMRC may not want to disseminate the curriculum. The contract will mitigate these risks as much as possible by possibly including a minimum time period for SMRC to sustain the program (with a goal of perpetuity) and incorporating a reversion clause stating the MBRF will obtain ownership of the brain health content if SMRC ceases to offer the curriculum. At that point, the MBRF can choose to disseminate the program itself or work with another partner. Every effort will be made to structure this initiative and the legal agreement to mitigate against such risks.

Please send any questions in advance that you would like Angelika, John, or the applicants to address prior to or during our committee meeting. We look forward to having a lively discussion and for you to meet our applicants.

Brain Health Outreach Update

Background

Angelika has continued to develop relationships with organizations that demonstrate a shared mission of educating consumers and/or healthcare providers on brain health and cognitive aging. Initial conversations have enabled her to share about the MBRF's strategic priorities around brain health education and outreach and begin to explore collaborative opportunities and synergies that may help the foundation advance these goals.

Meeting Summaries:

- American Academy of Neurology (AAN): Mike, Allison, Madhav and Angelika met with AAN leadership (CEO Mary Post, COO Jason Kopinski, and Public Engagement Manager Nicole Lussier) to discuss their new Brain Health Initiative, which launched in 2022. The goals of this initiative include advancing brain health through scientific discoveries, public policy, and patient and provider education. Over 100 stakeholders convened at the first Brain Health Summit in 2022. AAN invited MBRF representatives to the 2023 Brain Health Summit in Washington, DC which will take place on September 21. The AAN sees itself as a convener of organizations interested in this space and is still identifying their own role and priorities within this work. AAN and MBRF agreed to connect quarterly as our respective initiatives and strategies develop.
- Milken Institute: The Milken Institute, a nonprofit think tank, runs an Alliance to Improve Dementia Care. Their steering Committee includes over 100 organizations and thought leaders. Though previously focused on early detection and dementia care, they are now increasing their scope to include prevention and reduction. They expressed great interest in learning more about brain health education and continuing to explore synergies together. In 2021, the Milken Institute published a report which identifies many of the same gaps in primary acre that the MBRF is seeking to address entitled: "Building Workforce Capacity to Improve Screening and Diagnosis of Dementia."
- John A. Hartford Foundation: Angelika met with Rani Snyder, VP, to discuss the role that Brain Health education plays in the "Age-Friendly Health Systems" (4Ms Model) that was developed thanks to the John A. Hartford's funding. Rani connected Angelika with leaders at the Institute for Healthcare Improvement to learn more.

- Cognition in Primary Care: John Brady, Angelika, and Dr. Balza met with Dr. Barak Gaster, PI of the Cognition in Primary Care Model, to discuss integrations between a community-based brain health program into primary care. Angelika also connected Ron Lazar to Barak Gaster. Conversations are continuing as the pilot of the model continues in Washington State.
- Gerontological Society of America (GSA): Angelika has continued to meet with the KAER team to explore synergies related to their primary care model. The GSA team shared a very high-level concept paper related to a partnership with the Ohio Council for Cognitive Health, which is seeking to promote the use of the KAER model across the state, in community and clinical settings. GSA is looking to develop additional resources to guide brain health conversations across a variety of sectors in the community. Angelika is following up to learn more about how brain health education in the primary care and community-based settings plays a role in this initiative. The concept paper has been included in the meeting packet, and additional clarifying information is forthcoming by email, which will be shared with the Trustees.

Upcoming Meetings:

- AARP: Meeting with Sarah Locke to discuss Global Council on Brain Health and their new "Brain Health Action" Initiative.
- Institute for Healthcare Improvement: Meeting to discuss their implementation of the Age-Friendly Health Systems to learn more about the role that brain health plays in their "4Ms" model and discuss potential synergies.
- **BHAM**: eeting with Ron Lazar and Pamela Bowen to discuss their brain health initiative in two primary care clinics.



Proposal to the McKnight Brain Foundation Development of Brain Health Program

Self-Management Resource Center (SMRC) History/Capability

The Self-Management Resource Center started in 2017 with four partners who had all worked together for many years at the Stanford Patient Education Research Center, a part of the Department of Medicine at Stanford University School of Medicine. At that time the partners asked Stanford for the intellectual property that they had developed over many years and were given the property with the understanding they were starting a business to license the self-management programs and provide training and technical assistance. SMRC is a registered S Corporation in the state of California.

Over 40 years each of the self-management programs had been developed, evaluated, updated, and translated into widespread practice by the Stanford Patient Education Research Center. Many of these evaluations can be found at https://selfmanagementresource.com/resources/bibliography/. All of the programs, in both English and Spanish, have been found to improve health behaviors and health status. In many cases they have also reduced health care utilization. Programs are peer led, making them available in places people work and play and at times convenient to participants. This also means that in most cases leaders represent the populations they are serving.

There are currently six SMRC Programs: Chronic Disease Self-Management, Chronic Pain Self-Management, Diabetes Self-Management, Cancer: Thriving and Surviving, The Positive (HIV) Self-Management Program, and Building Better Caregivers. All of these programs are also available in Spanish and several in other languages. The Positive Self-Management Program will soon be replaced by an adaptation of the Chronic Disease Self-Management Program for older people living with HIV.

At the current time the programs are utilized by approximately 1000 organizations in 25 countries. These organizations are largely NGOs serving older populations such as senior centers, as well as State and local governmental agencies serving the same population. Recently, we have seen more uptake for health care organizations, specifically health care systems. Of those starting a workshop, 70% or more complete four or more of the six sessions. The Administration for Community Living (ACL) considers these completers. Data from previous studies indicate that to get maximum benefit, participants must attend at least four sessions. If the workshop were only four sessions, the completion rate would be about 50 percent. This and the amount of content, is the reason all current programs are six sessions. In the United States, SMRC programs have reached about a million people since 2010. About half of this utilization is driven by yearly grants offered by the ACL through Title II-D of the Older Americans Act to organizations throughout the United States for evidence-based programs. There are eight to ten grants per year, and each is for three years. Thus, there are about 30 active grants at any one time. The Arthritis Branch of CDC also funds states to offer evidence-based arthritis programs, including several of the SMRC programs. Participants do not usually pay for the program. Rather costs are born by grants, and or the organizations delivering the programs.

Each agency has its own criteria for evidence-based. In general, these include having undergone a controlled trial of about 6 months, been published in a peer-reviewed journal, and have the training and fidelity

infrastructure to translate the program to other agencies. Currently, we believe SMRC to be the largest distributor of evidence-based programs for both ACL and CDC Arthritis Branch.

SMRC has the capability to license programs and conduct training for program Leaders, Master Trainers (those who train Leaders) and cross-training (required to move a Leader from one program to another program). In all, SMRC conducts about 50 separate trainings a year. These trainings range from a few hours in one day to several hours over seven weeks. SMRC also offers technical assistance and keeps yearly records on the activities of each licensed agency as well as all Master Trainers (currently about 500).

To make these activities possible with a very small staff, SMRC has developed and maintains a robust website, https://selfmanagementresource.com/ with outfacing features for the public and interested organizations, as well as a platform for people to sign up for training or take out a basic license. In addition, there is a private portal through which training participants watch required videos, complete quizzes, and submit questions. Master Trainers are able to download training manuals, as well as submit their annual reports.

SMRC's relational database allows for sending annual reports to both organizations and Master Trainers and the collection of these reports online. SMRC is also able to obtain usage and other data reports from the database. Thus, the website and its many functions is a key part of the SMRC business model.

Data on participants comes from a recent national study as well as a data base maintained by the National Council on Aging. The following is a profile of those attending the Chronic Disease Self-Management Program. Mean age 66 years, 78% female. Hispanic 15%, African American 18%, Asian 5%, Native American 2%, White 71%. Because of the pandemic disruptions, yearly attendance is difficult to ascertain. Currently it is probably between 50 and 75 thousand a year.

Aims

- 1. To develop and pilot a 3–4-week, peer-led self-management program for the general public to be offered through community-based organizations and health care organizations.
- 2. To develop the materials for widespread translation:
 - 1) Leader's manuals for both in-person and virtual (via Zoom or similar platform) program delivery
 - Master Trainer manual for training new Leaders (not currently SMRC Leaders)
 - 3) Master Trainer manual for training current SMRC Leaders.
 - 4) Booklet for workshop participants.
- 3. To pilot the Brain Health Program twice via Zoom for 12 participants in each workshop.
- **4. To conduct two training courses of Leaders for the Brain Health Program.** The first will be for 12 people who are not current SMRC Leaders and the second will be for up to 20 current SMRC Leaders. These Leaders will all come from organizations already holding SMRC licenses. We will attempt to have at least some of the Leaders trained from organizations that will take part in the evaluation during years 2-3.
- 5. To enhance the SMRC website and database to include the following functions:
 - 1) Add information for the public and organizations about the Brain Health Program.
 - 2) Allow people to register on the website for brain health Leader and Master trainings.
 - 3) Allow organizations to apply for a stand-alone brain health license.
 - 4) Allow existing SMRC licensees to add the Brain Health Program to their existing license.
 - 5) Add the Brain Health Program to our program locator so that organizations and the public can locate where programs are offered in their area and find contact information.

- 6) Expand organizational and trainer private portal to allow downloads of Brain Health Program manuals and materials.
- 7) Add the Brain Health Program to our existing organizational and Master Trainer annual reports within the private portal.
- 8) For organizations only offering the Brain Health Program, develop a separate annual report form within the private portal.
- 9) Develop Brain Health Program usage-tracking reports.
- 10) Expand QuickBooks integration for invoicing the Brain Health Program licenses and training.
- **6. To repeat aims 1-4 in Spanish.** (This is not included in this budget or scope of work and would not take place until the second year of the project.)
- 7. To conduct an evaluation with a controlled design to determine the six-months efficacy of the Brain Health Program. Outcomes include improvements in health behaviors, such as endurance exercise, activities that engage the brain, discussing brain health with a health care professional, and reduced use of supplement, as well as improvements in self-efficacy and loneliness. (See U. of Washington proposal.)
- 8. To translate the Brain Health Program to widespread practice.
- 9. To determine the translation of the program to practice one year after public release. Metrics to include the number of organizations offering the program, the number of Leaders trained, the number of Master Trainers trained, the number of people who have attended one or more sessions.

Scope of work

<u>Aim 1</u>: To develop and pilot a 3–4-week, peer-led self-management program for the general public to be offered through community-based organizations and health care organizations. (Proposed structure of the brain health model and number of hours/sessions. Description of the various components of a session.)

a. Description of proposed program

The exact nature of the intervention is to be determined. There are at least two options, each of which would stand alone. The first option is a 4- to-5-week workshop with sessions of 2 to 2.5 hours per week. This workshop would focus on maintaining a healthy brain and working on improving exercise, healthy eating, loneliness, and participation in brain-engaging activities. We would probably also measure the use of supplements or "special" diets with the aim to reduce usage. Much of this workshop would take material in the current Chronic Disease Self-Management Program with supplemental content on brain health. The second option is a shorter workshop of 2-3 weeks with 1- to-1.5-hour sessions. This program would focus on the same topics but at an overview level with an outcome of increasing brain health knowledge.

With the first option we may be able to demonstrate some behavior change. It is doubtful that behavior change can be demonstrated with the second option. Our prediction is that translation would be wider with the second option, as organizations seems to like shorter programs and it is much easier to recruit participants. Participants will "like" both programs.

b. Structure of existing SMRC Programs

SMRC programs are all conducted by a pair of Leaders, the vast majority of whom are peers of the people attending and are not health professionals. Not only is this cost effective, it allows for modeling

of all activities by people who are relatable to the participants. Leaders receive either 30 hours of online training or 28 hours of in-person training conducted by Master Trainers. All Master Trainers have received Leader training, conducted at least three participant workshops, and have taken an additional nine hours of online training.

All programs are available in three delivery modes, face-to-face small groups (in person), virtual small groups, and telephone groups. The first two modes are 2.5 hours a week for six weeks and involve groups of 8-14 people, while the telephone mode is 1 hour a week for six weeks for groups of 3-6 people.

All programs are developed based on self-efficacy theory that states that one's belief or confidence in being able to do some is a strong predictor of future action. Self-efficacy is enhanced by skills mastery, modeling, reinterpretation of beliefs, and persuasion. All of these are systematically part of all SMRC programs.

<u>Aim 2</u>: To develop the materials for widespread translation: 1) Leader's manuals for both in-person and virtual (via Zoom or similar platform) program delivery; 2) a Master Trainer manual for training new Leaders (not currently SMRC Leaders); 3) a Master Trainer manual for training current SMRC Leaders; and 4) a booklet for workshop participants.

Because SMRC programs are largely conducted by peers (Leaders), and also to ensure fidelity of delivery, the programs are highly scripted with both the content and process detailed on a minute-by-minute basis for the entire program. This does not mean that the programs are designed to be "read". As Leaders are encouraged to use their own words and examples. In addition, the problems, decisions and action plans of each participant come from the participants and are not led or directed by the Leaders. Just as the Leader's manuals are scripted, the same is true for the manuals used by Master Trainers (those who train Leaders). Again, this is to ensure fidelity of training, as well as to allow the Master Trainers to check on specific Leader competencies such as being able to follow the manual, conducting brainstorming, action-planning and feedback correctly, dealing with problems as they arise, as well as being nonjudgmental.

All programs require a minimum of three manuals, the first for Leaders to facilitate workshops, the second for Master Trainers to train new Leaders, and the third to cross-train existing SMRC Leaders and Master Trainers in the new program. Each of these manuals is available in two formats, one for virtual (i.e., Zoom) delivery and one for in-person delivery. Thus, for the translation of the Brain Health Program we will develop a total of six manuals. While these are largely duplicative and existing SMRC manuals can be used, it will still be necessary to develop and produce six manuals.

We will start by developing a virtual Leader's manual for workshop delivery (basis for all other manuals), a virtual Master Trainer's manual for training Leaders who have never been trained in SMRC programs, and a virtual cross-training manual for training existing Leaders and Master Trainers. This will allow us to begin training Leaders in a timely manner. Second, we will develop an in-person Leader's manual.

During year one we will record (from a Leader Training) the activities in the Brain Health Program that are not in other SMRC programs. We will record the Leader training for non-SMRC Leaders so that the videos might be used as some of the materials for future virtual Brain Health Program training.

Finally, we will develop materials to be used by the participants. If we chose option 1 in Aim 1 (a longer more robust brain health workshop), the materials will probably include a book with some of the current content in *Living a Healthy Life with Chronic Conditions* (the book currently used for the SMRC Chronic

Disease Self-Management Program and the Diabetes Self-Management Program), as well as content specific to brain health. Another possibility for option 1 would be to use the current *Living a Healthy Life* book with a brain health supplemental booklet. If we choose option 2 in Aim 1, we will develop a short 20–30-page workbook with contents from the Brain Health Program. For example, we may include how to start and continue an exercise program and the basics of both the DASH and Mediterranean diets. All materials will have acknowledgement to the McKnight Brain Research Foundation as well as the foundation logo.

It is expected that it will take 8 months from the time of funding to completion of the first three manuals.

Aim 3: To pilot the Brain Health Program twice via Zoom for 12 participants in each workshop.

Workshops will be conducted via Zoom by SMRC staff for participants recruited from organizations already offering SMRC programs. We will seek participants who have not previously attended any SMRC programs. At the end of each workshop, we will hold a focus group with participants to discover what changes they would like in the program and the program will be adjusted based on the focus groups and observations of the SMRC staff.

Aim 4: To conduct two Leader trainings for the Brain Health Program.

The first will be for 12 people who are **not** current SMRC Leaders and the second will be for up to 20 **current** SMRC Leaders. All of the trainees will be recruited from organizations currently licensed to offer SMRC programs. We will record the Leader Training for non-SMRC Leaders so that the videos might be used as some of the materials for future virtual Brain Health Program training.

Aim 5: To enhance the SMRC website and database to include the following functions:

1) Add information for the public and organizations about the Brain Health Program; 2) Allow people to register on the website for brain health Leader and Master trainings; 3) Allow organizations to apply for a stand-alone brain health license (separate from the standard SMRC license); 4) Allow existing SMRC licensees to add the Brain Health Program to their existing license; 5) Add the Brain Health Program to our program locator so that organizations and the public can locate where programs are offered in their area and find contact information; 6) Expand organizational and trainer private portal to allow downloads of Brain Health Program manuals and materials; 7) Add the Brain Health Program to our existing organizational and Master Trainer annual reports within the private portal; 8) For organizations only offering the Brain Health Program, develop a separate annual report form within the private portal; 9) Develop Brain Health Program usage-tracking reports; 10) Expand QuickBooks integration for invoicing the Brain Health Program licenses and training.

<u>It is expected that it will take 9 months from the time of funding to completion of the website enhancements, which will occur concurrently with materials development.</u>

<u>Aim 6</u>: **To repeat aims 1-4 in Spanish.** This is not included in the current scope of work or budget but can be done after year one.

<u>Aim 7</u>: To conduct an evaluation with a controlled design to determine the six-months efficacy of the Brain Health Program. Outcomes include improvements in heath behaviors, such as endurance exercise, activities that engage the brain, discussing brain health with a health care professional, and reduced use of dietary

supplement, as well as improvements in self-efficacy and loneliness. The full list of outcomes will be developed in partnership with the MBRF, its Trustees, and, if desired, an MBRF-designated, advisory group for this project.

An evaluation is necessary if the Brain Health Program is to be recognized for funding by governmental organizations such as CDC and ACL. It is also an important, but not the only, consideration used by health care and other organizations when considering program adoption. Finally, it gives the program legitimacy in the eyes of health care providers. It is hoped that in the future Medicare will consider making evidence-based programs reimbursable for older Americans.

The details and budget for the evaluation are in a separate document supplied by the University of Washington.

Aim 8: To translate the Brain Health Program to widespread practice.

1. Licensing. SMRC will license the Brain Health Program.

A. Short Brain Health Program

All current SMRC licensees will be able to use the program without additional cost for the term of their current license. At the end of this term, there will be an additional fee for using the Brain Health Program.

Organizations not currently licensed by SMRC will pay a license fee for the Brain Health Program that will be based on the three-year term, much as are current SMRC licenses.

B. 4-5-week Brain Health Program

The Brain Health Program (assuming it is 4-5 weeks) will be licensed just as all other SMRC licenses. An organizational license allows that organization to offer any SMRC program for which it has trained Leaders. License fees are based on the total number of SMRC workshops that will be offered over three years. We currently have upward of 500 licensees. Our small licenses cover only one organization while larger licenses cover us to 30 organizations. Thus, any organization currently covered by a license will be able to add the Brain Health Program without additional fees. New organizations will take a license at whatever level they wish and have access to all SMRC programs. For information about current licenses see

https://selfmanagementresource.com/licensing/licensing-procedure-policies/

2. Training:

SMRC offers three types of training; 1) training for new SMRC Leaders (those who teach the programs to participants); 2) Cross-training for Leaders and Master Trainers (those who conduct Leader training). Cross-trainings are short trainings designed for those already trained in one SMRC program who wish to facilitate additional SMRC program(s); and 3) Master Training, which is 9 additional hours of training for those who are already Leaders and have conducted at least three workshops. Master Trainers can conduct Leader and cross-training for any programs in which they have been trained and have conducted at least one participant workshop.

Usually, the initial Leader training is in the Chronic Disease Self-Management Program with cross-training to all other programs. We can also conduct a Leader training for groups of 10-12 for any SMRC workshop.

Leaders for the Brain Health Program will be trained by either SMRC or Brain Health Master Trainers in one of two ways:

- 1) Full Leader training for those who have never received SMRC training. The length of this training will be determined by the length of the new program. If the new program is five weeks, training will be 2.5 hours, twice a week, for five weeks, with an additional 2.5-hour session in the week before the start of training to orient people to the training, answer questions, and give people their practice teaching assignments. During this training each trainee will participate in two practice teaches.
- 2) People who have previously received training in an SMRC program can become Brain Health Leaders by taking a cross-training. This training will be 2-5 hours in length, depending on the length of the new program. As part of this training, but pre-work not included in the 2–5-hour session, trainees will view videos of all parts of the Brain Health Program that are not part of existing SMRC programs.

Leader training can be offered by any licensed organization and is conducted by any pair of Master Trainers who are certified in the program for which Leaders are being trained. These trainings can be in person or via virtual platform such as Zoom. Leader training is also offered virtually several times per year by SMRC.

Master Training. SMRC trains Master Trainers for all programs together as the skills are common across programs. This training is typically 3 sessions of 3 hours each given over 3 weeks. To become a Master Trainer, one must: 1) have conducted 3 SMRC workshops to participants, 2) taken SMRC master training and been approved by SMRC staff, and 3) have facilitated at least one participant workshop for the SMRC program for which they are doing training. For the Brain Health Program there will be three ways to become a Brain Health Master Trainer: 1) a Leader who has conducted 3 brain health workshops can participate in a master training; 2) an existing SMRC Leader can take master training along with a Brain Health cross-training and facilitate one Brain Health program, or 3) an existing SMRC Master Trainer can take a Brain Health cross-training and conduct one Brain Health Program.

SMRC conducts all Master Trainings, currently via Zoom virtual platform.

3. Marketing:

SMRC has done little formal marketing other than participating in numerous professional meetings and webinars each year. We have active and ongoing relationships with several national organizations and governmental agencies including The National Council on Aging, The American Society for Aging, The Benjamin Rose Institute on Aging, The National Epilepsy Foundation, The Administration for Community Living, the CDC Arthritis Branch, The Pan American Health Organization, and the European Branch of the World Health Organization. We would collaborate with the McKnight Brain Research Foundation to expand knowledge of the new program to new organizations.

Our plan would be to release the program for general use at the end of the development year. Thus, it would be in general use during the evaluation phase of this grant. This release would include informing all existing licensed organizations and Master Trainers about the program and schedule cross-training for existing Leaders and Master trainers. The program availability would also be displayed on our website and included in all presentations. We estimate 500-2000 participants a year before the study completion and 5000 a year should the study show the intervention to be efficacious. We would be happy to collaborate with the Foundation on a national press release, if desired.

4. Sustainability Plan:

SMRC will own and sustain the program through income from licensing, training and royalties on any materials developed for the public not owned by the Foundation. The MBRF logo and acknowledgements will remain on all program materials. If SMRC decided to not continue the program, it would revert to the Foundation.

<u>Aim 9</u>: To determine the translation of the program to practice one to two years after public release. Metrics to include the number of organizations offering the program, the number of Leaders trained, the number of Master Trainers trained, the number of people who have attended one or more sessions.

SMRC receives yearly reports from all licensed organizations (due on the anniversary of their license) and from all Master Trainers during the first 2 months of each calendar year. The Brain Health Program will be a data point in these reports, and we should be able to capture the above data yearly.

Timeline

	Months 1-3	Months 4-6	Months 7-9	Months 10-12	Months 13-
Development Tasks	Develop the Brain Health Program Develop Virtual Leader's Manual Work with website developer to begin website modifications	Develop Virtual Master Trainer's Manual Develop In- Person Leader's Manual Develop participant materials Pilot the Brain Health Program Continue website modifications	Develop Virtual Cross-Training Manual Conduct first full Zoom Leader training for new Brain Health Leaders Hold focus group with new Leaders Develop In- Person Master Trainer's Manual Complete website modification	Modify Leader's Manual Conduct Leader/Master Trainer cross- training with current SMRC Leaders and Master Trainers Develop In- Person Cross- Training Manual	Spanish translation and pilot testing
Evaluation Tasks				Assist evaluator with selecting instruments and recruiting sites.	Assist with evaluation

SMRC Research Budget for Development of Brain Health Program	Proposed Budget	Notes
Year 1 Budget*		
Develop program content; five sessions of 2 hours each; or 3 sessions of one hour each	\$12,000.00	
Create Virtual Leader's Manual	\$3,000.00	Basis for all program content and manuals
Pilot The Brain Health Program	\$3,750.00	Pilot The Brain Health Program with new Leaders via Zoom, including recruitment of participants
Create an in-person Leader Manual	\$1,500.00	
Development of 2 Master Trainer's Manuals	\$9,000.00	One for training SMRC existing Leaders and one for people who are not already SMRC Leaders. The first training would be about 1.5-3 hours and the second about 5 to 20 hours, both on Zoom. We would also create 2 additional similar manuals for in-person Leader training
Make suggestions (revise) existing McKnight online material for the public, to also be used by workshop participants.	\$1,500.00	Revise booklet to create program specific materials
Enhance SMRC website to add product line	\$15,000.00	to include the following: 1) information about the Brain Health workshop, 2) Inclusion of Brain Health data collection to both the Master Trainer database and to the yearly licensing reports, 3) enhancing the training and registration public facing sites and database to include the Brain Health Program, 3) extending integration of billing and tracking functions for new program.
Train up to 20 existing SMRC Leaders to offer the Brain Health workshop	\$1,500.00	10 hours/\$1500 (the normal cost would be \$300 per trainee or \$6,000; \$4,500 in-kind)
Train 12 new brain health Leaders to offer the Brain Health workshop	\$3,700.00	25 hours/\$3700 (the normal cost would be \$1000 per participant or \$12,000 includes \$8,300 in-kind services.)
Website Maintenance, IT expenses, misc.	\$ 4,050.00	Website maintenance, IT, phones, insurance, utilities, credit card processing,
TOTAL Year 1	\$55,000.00	

above is \$150/hour

SMRC Research Budget for Development of Brain Health Program	Proposed Budget	Notes
Years 2-4 Budget		
Assist with the evaluation, \$10,000 a year (years 2-4) including up to \$1800 project related travel (ie conference) per year.	\$30,000.00	Evaluation years 2-4 \$10,000 a year direct cost with an additional \$ 1,000 indirect for a total of \$33,000; Assist the PI in study design, and instrument selection/design. Assist in recruiting organization to take part in the evaluation;
		Support organizations and Leaders throughout the study
		Conduct up to two Leader trainings and two cross- trainings during the evaluation study
		(Based on current training fees, this is an in-kind contribution of approximately \$30,000)
		Assist with data interpretation
Subtotal Years 2-4	\$30,000.00	
Website Maintenance, IT expenses, misc.	\$4,000.00	Website maintenance, IT, phones, insurance, utilities, credit card processing
		(\$1,333.33 per year)
Total Years 2-4	\$34,000.00 (\$11,333.333	If evaluation is completed by year 3, Year 4 payment will not be needed.
	per year)	
Grand Total, Years 1-4	\$89,000.00	
Total in-kind	\$68,800.00	See below
In-Kind Year 1	\$12,800	Year one reduced fees for training \$12,800
In-Kind Year 2	\$36,000.00	Year two (evaluation) reduced training fees \$36,000 (two leader trainings and two cross trainings)

\$20,000.00 No additional fees for current SMRC programs to offer the Brain Health Program. Assuming 20 percent (100 licensees) would take an additional license at \$200=\$20,000

Total In Kind \$68,800.00

Appendix: Questions and Answers Regarding the Evaluation

Why the proposed study differs than traditional randomized clinical trials?

In traditional clinical trials participants are chosen by narrow criteria (assuring homogeneity) and are followed in clinical settings. Data are collected by those trained in research protocols. None of these apply to the proposed study.

Participants will be very heterogenetic (demographic and health status). They will participate in real world settings. Their interest in the new Brain Health Program will be personal and not driven by the desire to participate in research. As such, the participant burden must be kept to a minimum.

The community settings offering the new Brain Health Program are not used to participating in research or in assuring the validity of data. As such the PI must set up systems to collect data directly from participants, generally by phone or computer survey, must monitor the data on a weekly basis to pick up anomalies in a timely manner so that, if necessary, participants can be contacted to if questions arise. In addition, the study team must stay in touch with study participants in ways that do not influence the outcomes but do assure the collection of post intervention data. While doing all of this the PI must stay in contact with and collect data, such as attendance from multiple community agencies. All of this must be done without burdening community organizations.

Why the University of Washington?

The University of Washing houses the deTornyay Center for Healthy Aging. This center is dedicated to addressing and embracing the changing needs of our population, building robust pathways to healthy aging that are supported by innovative nursing research and a nursing workforce knowledgeable about older adults. The proposed PI, Basia Belza PhD has a primary interest in and a long history of research and practice in Healthy brain, healthy aging, evidence-based health promotion programs, physical activity, public health interventions and policy.

UW houses the innovative and cutting-edge Cognition in Primary Care (CPC) Program directed by Dr. Barak Gaster. Supported by CDC and Davos Foundation. Dr. Belza has served as an integral member of the CPC team for the past 2 years.

Why Dr. Belza?

Dr. Belza holds an endowed Professorship and for 25 years has had funding and research experience relevant to the proposed project in the implementation and dissemination of evidence-based health promotions programs with a strong focus on gerontology. She has a successful record in establishing and maintaining community-based partnerships and is well known and trusted by the community-based organizations on which we will

depend upon to both implement the Brain Health Program and supply research participants for the proposed study.

Dr. Belza's research record for both funding and publications attest to her specific knowledge of and ability to complete complex, multi-site, community-based clinical trials such as the one proposed. In short, Dr Belza has the understanding, skills and track record to conduct the proposed study.

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors. Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Lorig, Kate R.

eRA COMMONS USER NAME (credential, e.g., agency login): KLorig

POSITION TITLE: Professor of Medicine, Emeritus

EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Boston University, Boston, MA	BS	06/1964	Nursing
University of California, San Francisco, San Francisco, CA	MS	06/1968	Nursing
University of California, Berkeley, Berkeley, CA	MPH	06/1978	Health Education
University of California, Berkeley, Berkeley, CA	DrPH	06/1980	Health Education

A. Personal Statement

I am a Professor Emeritus at Stanford University School of Medicine and have over 35 years of experience developing, evaluating, and translating into practice self-management programs for people with chronic conditions, caregivers, and cancer survivors. The Stanford Self- Management Programs are available in small group, the Internet, and mailed versions and initially developed for Latino patient populations with diabetes in the community for which the current study is proposed. All of the self-management programs have been evaluated for efficacy in long-term trials. These programs are currently used in approximately 30 countries and have reached over a million people. I have a track record of externally funded research which have led to the current work proposed in this grant. My current interests include: 1) Enhancing the reach of programs so that they are widely available and used by the public; 2) Exploring how to keep people engaged once they start the program and understanding how different forms of engagement affect outcomes; 3) Developing, evaluating, and disseminating programs for caregivers of those with cognitive impairment; 4) Exploring the hypothesis that if the individual choose their mode of receiving self-management education (small group, Internet, mail) the three programs will have similar positive effects; 5) Exploring how self-management can be integrated into new patterns of health care practice; 6) Patient engagement; 7) Exploring the role of self-tailoring and its effect on future health status. The proposed study fulfills my current interests and expertise in integrating selfmanagement of chronic disease into cancer care. As a co-investigator on this study, I will oversee the training of the community health workers for the delivery of the self-management education program in diabetes and the integration of this program as one of three evidence-based components.

My work, started with examining the effects of community-based education for those with arthritis. Over many years, the model we developed which is based on self-efficacy theory, has proven remarkably robust across cultures, languages, and conditions. The later includes chronic diseases, severe mental illness, chronic pain including those being tapered from opioids, and cancer survivors. During the pandemic, we expanded to remote virtual and telephone delivery. As far as I know, the model has never been used with burn survivors. I welcome this opportunity to expand to this very underserved population.

- 1. Ory MG, Smith ML, Patton K, Lorig K, Zenker W, Whitelaw N. Self- Management at the Tipping Point: Reaching 100,000 Americans with Evidence-Based Programs. J Am Geriatr Soc. 2013 May; 61(5):821-823.
- 2. Lorig K, Sobel DS, Stewart AL, Brown BW Jr, Bandura A, Ritter P, Gonzalez VM, Laurent DD, Holman HR. Evidence suggesting that a chronic disease self-management program can improve health status

- while reducing hospitalization: a randomized trial. Med Care. 1999 Jan; 37(1):5-14.
- 3. Ahn S, Basu R, Smith ML, Jiang L, Lorig K, Whitelaw N, Ory MG. The impact of chronic disease self- management programs: healthcare savings through a community-based intervention. BMC Public Health. 2013 Dec; 13:1141. PMCID: PMC3878965.
- 4. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA. 2002 Nov; 288(19):2469-2475.

B. Positions, Scientific Appointments, Honors

Positions an	<u>d Employment (No foreign affiliations to disclose)</u>	L
106/_1067	Page Corns Volunteer Nurse Valdivia Chile	-

1964-1967	Peace Corps volunteer nurse, valdivia, Chile
1971-1974	Community Development Specialist, University of California Extension, Santa Cruz, CA
1975-1977	Clinical Advisor, California Urban Indian Health Council
1978-1995	Research Associate, Senior Research Scientist, Stanford Patients Education Research Center,
	Stanford University School of Medicine, Stanford, CA
1985-present	Clinical Associate Professor, University of California, San Francisco, School of Nursing, San
	Francisco, CA
1995-2002	Associate Professor (Research), Division of Immunology and Rheumatology, Stanford
	University School of Medicine, Stanford, CA
2002-2008	Professor (Research) of Medicine, Division of Immunology and Rheumatology, Stanford
	University School of Medicine, Stanford, CA
2008-present	Professor (Research) of Medicine Emerita Division of Immunology and Rheumatology, Stanford

2008-present Professor (Research) of Medicine, Emerita, Division of Immunology and Rheumatology, Stanford University School of Medicine, Stanford, CA

Honors and Awards

1997 Fe	llow, Societ	y of Behavio	ral Medicine
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- 2000 Distinguished Fellow, Society for Public Health Education
- 2003 The Molly Mettler Award for Leadership in Health Promotion
- 2007 Master American College of Rheumatology

C. Contribution to Science

- 1. Early writings linking changes in self-efficacy to changes in health care status.
 - a. Lorig K, Laurin J: Some notions about the assumptions underlying health education. Health Educ Q. 1985 Fall; 12(3):231-243.
 - b. Lorig K, Seleznick M, Lubeck D, Ung E, Chastain RL, Holman HR: The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. Arthritis Rheum. 1989 Jan; 32(1):91-95.
- 2. Developing self-management programs that enhance self-efficacy and conducting the studies demonstrating that self-efficacy can be changed and that these changes can lead to improved health behaviors and health status.
 - a. Lorig K, Chastain R, Ung E, Shoor S, Holman HR: Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis Rheum. 1989 Jan; 32(1):37-44.
 - b. Lorig K, Ritter PL, Ory MG, Whitelaw N. Effectiveness of a Generic Chronic Disease Self-Management Program for People With Type 2 Diabetes: A Translation Study. Diabetes Educ. 2013 Sep-Oct; 39(5):655-663.
- 3. Developing, evaluating, and disseminating more than a dozen different self-management interventions for people with chronic conditions, cancer survivors, and caregivers. These interventions are available in multiple languages and multiple modes of delivery.
 - a. Lorig KR, Sobel DS, Stewart AL, Brown BW Jr, Bandura A, Ritter P, Gonzalez VM, Laurent DD, Holman HR. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999 Jan; 37(1):5-14.
 - b. Chen Z, Koh PW, Ritter PL, Lorig K, Bantum EO, Saria S. Dissecting an Online Intervention for Cancer Survivors: Four Exploratory Analyses of Internet Engagement and Its Effects on Health Status and Health Behaviors. Health Educ Behav. 2015 Feb; 42(1):32-45.

- 4. Demonstrating that peer-led, community-based programs affect health behaviors, health status, and health care utilization. Also demonstrating that programs can reach the hard-to-reach.
 - a. Lorig K, Laurent DD, Plant K, Krishnan E, Ritter PL. The components of action planning and their associations with behavior and health outcomes. Chronic Illn. 2014 Mar; 10(1):50-59.
 - b. Lorig K, Ritter PL, Pifer C, Werner P. Effectiveness of the Chronic Disease Self-Management Program for Persons with a Serious Mental Illness: A Translation Study. Community Ment Health J. 2014 Jan; 50(1):96-103.
- 5. Early explorations on the role of self-tailored interventions and their effect on health status
 - a. Ritter PL, Ory MG, Laurent DD, Lorig K. Effects of chronic disease self-management programs for participants with higher depression scores: secondary analyses of an on-line and a small-group program. 2014 Dec; 4(4):398-406. PMCID: PMC4286546.

Extended List of Published Work can be found:

http://patienteducation.stanford.edu/bibliog.html

D. Research Support

Ongoing Research Support

OPD-1610-37007 (Beth Darnall - SPO 128277) Patient-Centered Outcomes Research Institute

02/01/18 - 03/01/24

Comparative Effectiveness of Pain Cognitive Behavioral Therapy and Chronic Pain Self-Management Within the Context of Opioid Reduction

1R01AG057855-01A1 (Kate Lorig - SPO 133898)

09/30/18 - 05/31/23

NIH / University of California, San Francisco

Evaluating the Effectiveness of an Online Small-Group Self-Management Workshop for Rural Caregivers of Individuals with Alzheimer's Disease and Related

Completed Research

CERSI FDA project (Mackey)

03/01/20 - 08/31/20

Characterizing Risk-Benefit Tradeoff in Opioid-based Chronic Pain Treatment

5R01AT00856105 (Beth Darnall - SPO 115056)

09/01/15 - 05/31/20

National Institutes of Health

Single Session Pain Catastrophizing Treatment: Comparative Efficacy & Mechanisms

To test the efficacy of a novel treatment for pain catastrophizing developed and piloted at the Stanford Pain Management Center.

June 14, 2023

Angelika Schlanger, PhD Executive Director McKnight Brain Research Foundation

Dear Dr. Schlanger,

It is with pleasure we submit this proposal "Evaluation of a Novel Community-Based Program on Brain Health for Adults and Older Adults" for consideration for funding from the McKnight Brain Research Foundation. We believe our proposal responds to the Foundations' needs to develop an evidence-base for a soon-to-be developed Brain Health Program by Dr. Kate Lorig and her team at the Self-Management Resource Center.

Please let us know if your need additional information and/or have questions. It has been a delight learning about the incredible work of the McKnight Brain Research Foundation and working with you in putting together this proposal. We look forward to hearing back from you after you have presented this proposal to the trustees of the McKnight Brain Research Foundation.

Sincerely,

Basia Belza

Basia Belza, PhD, RN, FAAN, FGSA de Tornyay Endowed Professor in Healthy Aging Director, de Tornyay Center for Healthy Aging Adjunct Professor, School of Public Health Box 357266, School of Nursing University of Washington, Seattle, WA Cell (206) 947-1954 basiab@uw.edu

Evaluation of a Novel Community-Based Program on Brain Health for Adults and Older Adults

Proposal submitted to the McKnight Brain Research Foundation

Basia Belza, PhD, RN, FAAN, FGSA basiab@uw.edu
de Tornyay Endowed Professor of Aging, School of Nursing
Director, de Tornyay Center for Heathy Aging
Adjunct Professor, School of Public Health
University of Washington, Seattle

Background

With the increasing number of adults reporting concerns with cognitive changes, communityand evidence-based programs are needed with a focus on educating and encouraging behavior change to maintain and improve brain health. The purpose of this study is to evaluate an innovative and newly developed, community-based Brain Heath Program for adults and older adults.

Aims

The aim of this study is to conduct an evaluation with a controlled design to determine the six months efficacy [improvements in heath behaviors (endurance exercise, activities that engage the brain, discussing brain health with a health care professional and family, and less use of non-evidence based dietary supplements), self-efficacy and loneliness] of the Brain Health Program.

Theoretical Framework

This study is based on the concept of self-efficacy which is a person's belief in their ability to complete a task and/or achieve a goal. It encompasses a person's confidence in themselves to control their behavior, exert an influence over their environment, and stay motivated in the pursuit of their goal. The concept of self-efficacy is central to Bandura's social cognitive theory where self-efficacy is part of the self-system comprised of a person's attitudes, abilities, and cognitive skills (Bandura, 1977). Similar to other self-management workshops, the Healthy Brain Program is interactive and includes content and activities to increase participants confidence, physical and psychological well-being, knowledge, and motivation to manage challenges associated with one's health.

Research Design

We propose to use a multi-site, wait-list controlled trial with a pre and post evaluation design. We will invite community organizations and healthcare-based sites located in the United States that currently participate in the Self-Management Resource Center (SMRC) to apply as a consortium site for our study. We will request the following information in their application: name, type, and size of organization; characteristics of clients served; and geographical location. We will use maximum variation purposive sampling to select 20 community organizations and healthcare-based sites representing diverse organization size and type, provider characteristics, and geographic area to aid with generalizability of evaluation findings. This purposive sampling will also prioritize organizations that engage ethnically-diverse older populations. Each community organization will recruit at least 15 participants. With support from

the participating organizations, project team members will screen, enroll, consent and cluster randomize by site (intervention or wait list), and collect data on 15 participants per site (total n=300 participants).

Consortium Sites. The SMRC has long-standing partnerships with 1,000 community organizations throughout the world. The organizations are public and private, federal and state, located in rural and urban areas, and many reach an ethnically diverse group of adult and older adults. These respected organizations have offered the Chronic Disease Self-Management program in the past and successfully reached underserved communities. The SMRC will invite community organizations to serve as consortium sites through an application and selection process. Informed by the McKnight Brain Health Foundation Advisory Group, the project team will select 20 of the sites that represent diversity in geography, type, and audience served, and have a history of being successful at recruiting participants into self-management courses. Consortium sites will agree to recruit participants and refer participants to the project team to screen, lead at least 2 Brain Health Programs with 12-15 participants each, and retain at least 15 participants from baseline to 6 months, facilitate completion of questionnaires, and submit action plans and rosters to the project team. In return consortium sites will receive instructor training led by the staff of the SMRC on the Heathy Brain Program and \$20 once action plans and rosters are submitted.

Informed consent. A trained project team member will collect informed consent prior to enrollment into the study by phone and/or Zoom. The informed consent document details the study procedures, risks, benefits, site contact information, and the nature of confidentiality and voluntary participation. The consent process also covers information on compensation. Potential participants will receive a copy of an informed consent document.

Eligibility Screening and Inclusion Criteria. Potential participants will either call, text, or email the study-specific phone and/or email address. Project staff will monitor the incoming mail and messages. Participants will be screened for eligibility using a screening instrument that identifies: they are naïve to self-management Programs within the past 3 years, 40 years or older, are able to read and write English, living in a home or independent congregate living, willing to participate in either the intervention or the wait list control, and able and willing to provide informed consent.

Randomization. Each consortium site will be responsible for recruiting participants through posting flyers, announcing in agency newsletters, posting on websites, and/or giving presentations. The project team will screen and determine eligibility and then participants will be consented and complete the baseline questionnaires. The participant will then be randomized to either the intervention or the wait list. Randomization will be stratified by site using a permuted block design. For those who are randomized to the intervention group information will be provided as to when and where the Program will be held. For those who are randomized to the wait list group they will be provided information that they will be eligible to take the Program in 6 months. In order to keep the attention of the wait-list participants, birthday cards will be sent as well as cards to recognize national holidays during the wait list period.

Overview of Data Collection Time Points. We will conduct simultaneous assessments for both the intervention and the wait-list arms. All outcome measures will be assessed at baseline and 6 months after the baseline assessment. Participants will be offered \$10 for

completion of the study materials at baseline and at 6 months for a total of \$20 per participant. The purpose of conducting an assessment six months after the intervention is to evaluate if the knowledge and behavior changes have been sustained.

Measures. Once we have confirmed with the McKnight Brain Research Foundation Advisory Group the key outcomes, the project team will select appropriate measures (Table 1). Among the outcomes will be those that demonstrate the six critical elements to age successfully and maintain your brain health Brain Health - MBRF (mcknightbrain.org). The measures selected will have been previously published and validated. We will also provide open-ended questions to capture additional information that participants would like to share.

Table 1. Proposed Primary and Secondary Outcomes Measured at Baseline and 6 months (Note: This list will be revised based on input from the McKnight Brain Research Foundation Advisory Group. Once outcomes are approved then measures will be identified)

Primary or Secondary Outcome	Outcome	Measure
Health Behaviors- Primary	Activities to engage the brain	TBD
Health Behaviors-Primary	Communication about brain	Chronic Disease Self-Efficacy
	health with a health care	Scale related to talking with
	provider and family	provider about brain health
Health Behaviors-Primary	Healthy eating	TBD
Health Behaviors-Primary	Sleep and exercise	Single-item exercise and sleep
		were developed and validated by
		SMRC for the Chronic Disease
		Self-Management (CDSM) suite
Health Behaviors-Primary	Smoking behavior	Self-report
Health Behaviors-Primary	Less use of non-evidence	Knowledge item
	based dietary supplements.	
Self-Efficacy-Primary		Chronic Disease Self-Efficacy
		Scale related to brain health,
		exercise, nutrition, and sleep
Health status-Secondary	Depression	PHQ-8 (Kroenke, 2009)
Health status-Secondary	Self-rated health	SF-36 (Stewart, 1992)
Health status-Secondary	Knowledge	Brain Health approaches (TBD)
Health status-Secondary	Loneliness	UCLA-Loneliness (Hughes, 2004)

At the completion of each Healthy Brain Program, instructors will submit online to the project team: 1) attendance roster, 2) participant action plans (to see what areas are being identified as areas to change), and 3) brief comments about what went well and what could be improved. The use of an action plan allows for participants to self-tailor the intervention which is a novel approach. People succeed because they can select their own action plan. Instructors will be provided \$20 for submitting these materials.

Participant demographics to be collected include: date of birth, ethnicity, gender, marital status, and number of people you live with. Additionally, we will ask an open-ended question: Why are you interested in this program?

Data Collection

Prior to attending their first class, participants will be asked to complete a questionnaire using a QR code, online link, or phone administration by a member of the project team. If a participant has not completed the questionnaire before the first class, attempts will be made to secure the participants participation in completing it on-line by phone, or on paper before the second session. Data will be securely managed using REDCap at University of Washington, Seattle, Washington. At six months, data will be collected by the method preferred by the participant at baseline. If the first attempt at collecting the 6-month data is not successful, two follow-up attempts will be made by phone.

Table 2. Recruitment, Enrollment and Retention Plan

		N	%
1	Total number of study participants expected to be screened	600	
2	Estimated number of participants to be eligible	400	
3	Estimated number of participants to enroll	360	
4	Target sample size	300	
5	Total number of consortium sites that will enroll participants	20	
6	Estimated percentage of participant drop out		20

Statistical Analysis

All data will be analyzed using intent-to-treat principles. Participant demographic characteristics, (TBD) and baseline levels of the primary and secondary health behaviors and statuses will be summarized using descriptive statistics, means and standard deviations for continuous measures and numbers and percentages for categorical measures. For the primary outcomes, change in health behaviors from baseline to posttreatment will be analyzed using analysis of covariance (ANCOVA), with treatment group assignment as the between-subjects factor and an interaction term between assessment and group, and with the baseline level of the outcome measure as a covariate. Changes in the secondary outcomes of health statuses will be analyzed in a similar manner. Subgroup analyses based on patient demographics (TBD) will also be conducted.

Interviews

Interviews will be conducted with a sample of 20 participants (1-2 participants from each of 20 consortium sites) about their experiences with the Healthy Brain Program. An interview guide will be developed and piloted prior to using it with the 20 participants. The interviews will be conducted in small groups of 5-6 participants within a month of completing the Healthy Brain Program. Interviews will be conducted on Zoom by a member of the project team and recorded. The transcripts will be analyzed for key themes and a manuscript will be prepared for submission to a peer reviewed journal.

Administration for Community Living (ACL) Definition of Evidence-Based Programs. One way to assess whether Older Americans Act (OAA) Title III-D funds can be spent on a program, is the evidence-based program needs to meet the criteria in Table 3. This study will be addressing all 5 of the criteria. We will be measuring health outcomes, using an experimental design with random assignment and a wait-list group, and plan on publishing our findings in a content and methods relevant peer-reviewed journal. Should the manuscript not be accepted at the first journal which we submit it to, we will revise and submit to a second relevant and peer-reviewed journal and so on until the manuscript is accepted with the goal of publishing to meet the ACL's definition of an evidence-based program. We will be offering the program at multiple

consortium sites and are committed to developing and distributing dissemination products that target lay audiences.

Table 3. Administration for Community Living (ACL) Definition of Evidence-Based Programs Health Promotion | ACL Administration for Community Living

- 1. Demonstrated through evaluation to be effective for improving the health and well-being or reducing disease, disability and/or injury among older adults; *and*
- 2. Proven effective with older adult population, using Experimental or Quasi-Experimental Design;* *and*
- 3. Research results published in a peer-review journal; and
- 4. Fully translated** in one or more community site(s); and
- 5. Includes developed dissemination products that are available to the public.
- *Experimental designs use random assignment and a control group. Quasi-experimental designs do not use random assignment.
- **For purposes of the Title III-D definitions, being "fully translated in one or more community sites" means that the evidence-based program in question has been carried out at the community level (with fidelity to the published research) at least once before. Sites should only consider programs that have been shown to be effective within a real-world community setting.

Institutional Review Board Approval

Our team at University of Washington will prepare a human subjects research application for review by our Institutional Review Board (IRB). Previous experience with similar types of evaluations suggests that this project will be determined exempt for program evaluations. We will conduct safe, ethical research: All survey and interview instruments will include a brief introduction about the purpose of this project, potential risks and benefits, and what we will do to protect confidentiality. We do not anticipate more than minimal risk to participants as the questions they will be asked are similar to what is currently required when participating in other evidence-based programs as part of routine data collection. While we believe there is societal benefit to conducting this study for improving future access to care, individual study participants may not directly benefit from participating. Participants can opt out of any surveys, choose to skip any questions, and stop participating in a survey at any time. Data will be stored in REDCap, a secure and online database.

Table 4: Proposed Timeline

		Period 1		Period 2			Period 3			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2
Hire, train staff	Х									
Convene advisory group	Х		Х		Χ		Χ		Х	
Develop and pilot recruitment materials	X									
Finalize measures and develop online platform for data collection	Х									
Apply and obtain Institutional Review Board (IRB) approval		Х								

Develop and pilot	Χ								
interview guide									
Train consortium sites on	Χ								
recruitment, enrollment,									
and data collection									
Enroll and offer Program		X	Χ	Χ	Χ	Χ	Χ		
to intervention and									
waitlist participants									
Collect and enter data at		X	Χ	Χ	Χ	Χ	Χ	X	
baseline and 6 months									
Conduct interviews with				Χ	Χ	Χ	Χ		
selected participants									
Analyze data							Χ	Χ	Χ
Prepare final report and								Χ	Χ
community-oriented									
dissemination material(s)									
Write and submit a									Χ
manuscript(s) to a peer-									
reviewed journal									

*Advisory Group

The McKnight Brain Health Foundation will be responsible for assembling an Advisory Group representing various stakeholders including trustees, members of the McKnight Brain Research Foundation Institutes, health care providers representing various disciplines, and consumers. The Advisory Group will provide input in to the study protocols, selected outcomes, and other study specific guidance. The Advisory Group will meet every 6 months, or more frequently if needed. The UW project team is available to make recommendations and help identify participants for the advisory group if so requested by the Foundation.

Table 5: Proposed Deliverables by Time Period

Period 1	Period 2	Period 3
Two trained graduate students		
Two advisory group meetings	Two advisory group meetings	Two advisory group meetings
and bimonthly team meetings	and bimonthly team meetings	and bimonthly team meetings
Recruitment flyer and		
marketing materials		
Approved IRB application		
Finalized survey measures		
Onsite survey platform		
Finalized interview guide		
20 consortium sites trained in		
recruitment and data collection		
Recruit, screen and enroll 100	Recruit, screen, and enroll	
participants	200 participants	
Baseline data collected and	Baseline data collected and	
entered for 100 participants	entered for 200 participants	
	Six-month data collected and	Six-month data collected and
	entered for 300 participants	entered for any remaining
		participants

Birthday and/or thank you notes	Birthday and/or thank you	
sent to 100 participants	notes sent to 200 participants	
	Conduct 2 focus groups with	Conduct 2 focus groups with a
	a total of 10 participants	total of 10 participants
		Final written report
		Submit two manuscripts to
		peer-reviewed journals
		Submit an abstract and
		present at a conference
		Prepare a community-oriented
		dissemination product
Quarterly updates and bi-	Quarterly updates and bi-	Quarterly updates and bi-
annual written reports	annual written reports	annual written reports
submitted to the Foundation	submitted to the Foundation	submitted to the Foundation

Personnel

Basia Belza, PhD, RN, FAAN, GSA, Principal Investigator (10% for 30 months) will be responsible for the overall direction and administration of the proposed study and will work closely with Dr. Kate Lorig, developer of the Healthy Brain Program. Dr, Belza, the de Tornyay Endowed Professor in Aging and Director of the de Tornyay Center for Healthy Aging at University of Washington has extensive experience testing and disseminating evidence-based programs and working in the cognitive health space. Dr. Belza will oversee the implementation of the all research components including study design, oversee the preparation of databases, data collection process and forms, and liaise with the SMRC. She will oversee the regulatory components, training, human resources, and study protocols. She will work with the consortium sites to assure recruitment, screening, and enrolling participants is per protocol. She will lead biweekly team meetings. Dr. Belza will monitor study progress, assess recruitment benchmarks, and adjust recruitment strategies accordingly. She will participate in quarterly check-ins on Zoom with the key contacts at the McKnight Brain Research Foundation and submit bi-annual reports to the McKnight Brain Research Foundation. Drs. Belza will monitor the budget and see that funds are spent appropriately and judiciously to complete the study. Dr. Belza will establish. implement, and evaluate plans for data management and quality control. Upon completion of the study, Dr. Belza will convene discussions of data interpretation with the study team, study participants, and McKnight Brain Research Foundation Advisory Group and lay out plans for the preparation of scholarly manuscripts and community-oriented action briefs and the dissemination of the findings at scientific meetings (e.g. Gerontological Society of America, American Academy of Neurology, American Federation for Aging Research, Alzheimer's Association International Conference), public forums, and to our consortium sites. Dr. Belza will prepare the final report to the McKnight Brain Research Foundation and be responsible for other activities related to study closeout.

Kenneth Pike, PhD, Statistical Consultant (2.5% Yr 1) will provide statistical analysis expertise. Dr Pike has 25 years of NIH funded clinical research experience as a research scientist and statistical consultant. He will assure that the plan and execution of the study design meets the ACL criteria for using an experimental design and randomization. He will be available to address methodological issues that surface as well as proposing ways to analyzing the data when not all participants change on all variables.

Boeun Kim, PhD, RN, MPH, Data Manager (\$5,000 each Y2-Y3) will contribute methodological and statistical analysis expertise. Currently a post-doctoral scholar at John Hopkins University, Dr. Kim has training as a nursing scientist and in statistics, she brings a wide range of experience working on health-related studies employing meaningful outcomes in areas of brain health, older adults, and the built environment. Dr. Kim has completed additional training in statistical methods beyond her PhD and has worked with complex data sets and designed REDCap data bases and surveys, and worked with small and large research teams and has disseminating findings in peer-reviewed journals. She has provided statistical consultation on other projects with Dr. Belza for 8 years as well as worked with other research scientists from multiple disciplines and universities.

Graduate Research Assistants (RA) (TBD) (25% for 30 months for two students) Graduate nursing students at the University of Washington School of Nursing will be hired and trained to serve as members of the project team. These will be students who have knowledge of, passion for, and expertise in working with community partners and cognitive health. Responsibilities will include working with consortium sites to recruit, screen, and enroll participants. They will develop and pilot a recruitment flyer and determine optimal approaches to get it to potential participants at the consortium sites. They will be responsible for staying in touch with participants, not to influence outcomes but to assure collection of complete 6-month post intervention data. This might include but not be limited to follow up with participants either by phone or online and sending out, for example, birthday and holiday cards. Additionally, the RAs will monitor the data on a weekly basis to identify any anomalies so if necessary participants can be contacted to clarify responses.

Participant Incentives (\$20/participant x 300 participants for \$6,000 in Yrs 1-3). Based on our prior experience, participant incentives for data collection reduce the likelihood of study attrition. All participants will be invited to complete assessments at two time points. For this additional time, participants will receive \$10 at baseline and \$10 at 6 months.

Instructor Incentives (\$20/instructor x 30 instructors for \$600 in Yrs 1-3). Instructor incentives will be provided for turning in the roster and participant action plans for having conducted a Healthy Brain Program.

Travel Costs (3 people @ 1 trip/each). Funds are budgeted for Dr. Belza, a project team member, and an instructor of the Brain Health Program to travel to one relevant professional and/or lay conference that focuses on championing research in cognitive health such as but not limited to the Gerontological Society of America annual conference. Budgeted are costs for airfare, ground transportation, conference registration, and per diem.

Laptops: Three low priced laptops at \$1,250 each for a total of \$3,750 will be used by the graduate research assistants and the data manager. Laptops will be used to communicate with team members, consortium sites, and participants either through emails or Zoom meetings. They will be used to check the participants are completing surveys. For participants who do not use computers project team members will interview participants on the phone and enter data directly into REDCap using their computer. Communications with team members will occur through emails and a shared drive. The UW will provide the software for the computers including Microsoft Office, REDCap, PowerPoint, statistical software, and other relevant software to make marketing and other dissemination materials.

Table 6: Budget*

	T	444.000.4	444 50005	444 100 000	1
		4/1/2024 -	4/1/2025 -	4/1/2026 -	
		3/31/2025	3/31/2026	9/30/2026	
		Period 1	Period 2	Period 3	All Periods
	Salaries				
01 Salaries	Details	\$89,104		\$46,585	
Basia Belza, Principal Investigator	10% effort	\$19,843	\$20,637	\$10,731	\$51,211
Research Assistant	25% effort	\$29,718	\$30,907	\$16,071	\$76,696
Research Assistant	25% effort	\$29,718	\$30,907	\$16,071	\$76,696
Kenneth Pike, Statistical Consultant	2.5% effort Year 1 only	\$2,961	\$0	\$0	\$2,961
TBN Post-Award Manager	10% effort	\$6,864	\$7,139	\$3,712	\$17,715
Benefits (All staff)		\$18,796	\$18,621	\$9,683	\$47,100
Total Personnel		\$107,900	\$108,211	\$56,268	\$272,379
	Other Costs				
Service Contracts	Details	\$2,600	\$7,600	\$7,600	\$17,800
Participant incentives	20 @ \$100 yearly	\$2,000	\$2,000	\$2,000	\$6,000
Instructor Incentives	20 @ \$30 yearly	\$600	\$600	\$600	\$1,800
Boeun Kim, Data Manager Consultant	Years 2 & 3	\$0	\$5,000	\$5,000	\$10,000
Other Contractual Services		\$0	\$0	\$5,100	\$5,100
Conference registration	Year 3 only (3 attendees)	\$0	\$0	\$2,100	\$2,100
Publication Costs	Year 3 only	\$0	\$0	\$3,000	\$3,000
Travel		\$0	\$0	\$5,400	\$5,400
Conference ground transportation	Year 3 only (3 attendees)	\$0	\$0	\$300	\$300
Conference per diem	Year 3 only (3 attendees)	\$0	\$0	\$2,700	\$2,700
Conference airfare	Year 3 only (3 attendees)	\$0	\$0	\$2,400	\$2,400
Supplies and Materials		\$3,750	\$0	\$0	\$3,750
Laptops for Research Staff	3 @ \$1250/each	\$3,750	\$0	\$0	\$3,750
Total Other Direct Costs		\$6,350	\$7,600	\$18,100	\$32,050
Total Project Costs		\$114,250	\$115,811	\$74,368	\$304,429

^{*}The McKnight Brain Research Foundation does not cover indirects therefore no indirects are included in the proposed budget.

Budget Note: In-kind contribution: The UW project team will conduct a scoping review of the published literature on brain health programs for consumers.

Resources Available at the UW School of Nursing

The UW, founded in 1861 is one of the nation's premier educational and research institutions. UW faculty and staff are the backbone of the school's continued top-ranking position committed to the pursuit of excellence in education, research, and community service. Ranked No. 16 in the world on the 2020 Academic Ranking of World Universities, the UW educates more than 54,000 students annually. All faculty at the UW are required to attend training on the ethical conduct of research. All trainees have instruction in the nine elements of responsible conduct of research (I.e., data acquisition, management, sharing, ownership, mentor/trainee responsibilities, publication practices and responsible authorship, peer review, collaborative science, protection of human subjects, research involving animals, research misconduct, and conflict of interest and commitment).

University of Washington School of Nursing (SoN). Established as an independent school within UW Health Sciences in 1945, the UW SoN has been a top-ranked school in the nation since 1984, when the first national survey of nursing schools was conducted. The SoN is

organized as an autonomous school within the Health Sciences Center. Faculty members have computers, office supplies, and access to equipment such as printers and photocopiers. In addition, they have access to conference rooms in which their research team can meet and conduct trainings. Research is at the core of the school's mission to improve education, practice and patient outcomes. As such the research facilities of the SoN are extensive, and the Dean and the Graduate Faculty have made research and research training in Nursing Science a priority. The SoN consistently ranks among the top schools for overall research grant funding, receiving more than \$11 million in total research support from a wide variety of government and non-government sources in FY 2021. With more than 200 active and pending research projects, over 30 of which are funded through NIH and related agencies, the SoN ranks among the highest for NIH funding among nursing schools in the country. Our strategic research initiatives inform our faculty research and include four key areas:

Office of Nursing Research (ONR). The ONR provides an infrastructure which supports the SoN's research mission to advance nursing science. ONR offers statistical and research design, and consulting in the SoN. The Associate Dean for Research (ADR) is responsible for overseeing the infrastructure for all aspects of research within the SoN. The ADR is available to support researchers at every stage of the research project development and implementation; assist individual investigators with identifying which of the UW core facilities can house and support projects; help facilitate networking within the SoN, the UW, and the research community as well as assist in the development of the researchers' long-term program of research and career goals. The ADR facilitates faculty access to resources that address issues in grant preparation including methodology, analysis, statistical methods, grant form preparation, and scientific writing. The ADR leads the Group Consultations designed to help faculty develop and critique grant applications. Reviewers are made up of faculty from the SoN or other units on campus who have relevant experience with research design, analysis, the subject matter, and/or have served on internal and external grant review committees.

References

Bandura, A (1977). Self-efficacy: toward a unifying theory of behavioral change. Psychological Review, 84, 191–215.

Isaacson R et al (2018). The clinical practice of risk reduction for Alzheimer's disease: A precision medicine approach, Alzheimer's Dement, 14(12): 1663–1673. doi: 10.1016/j.jalz.2018.08.004

Isaacson R (2019). Individualized clinical management of patients at risk for Alzheimer's dementia. Alzheimer's Dement. 2019 Dec; 15(12): 1588–1602. doi: 10.1016/j.jalz.2019.08.198

Kroenke K, Strine TW, Spritzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. J Affect Disord. 2009; 114(1-3):163-73

Livingston G et al (2020). Dementia prevention, intervention, and care: 2020 report of the *Lancet* Commission. Lancet, 396, 413-446.

McKnight Brain Research Foundation Brain Health - MBRF (mcknightbrain.org)

National Academies of Sciences, Engineering, and Medicine (2015) Cognitive Aging: Progress in Understanding and Opportunities for Action. Washington, DC: The National Academies Press. https://doi.org/10.17226/21693.

Stewart A, Ware J (1992). Measuring Functioning and Well-being: The Medical Outcomes Study Approach. Duke University Press.

Appendix A: Proposal for the Conduct of a Scoping Review: In-Kind Contribution

A scoping review is a preliminary assessment (knowledge synthesis) of extent (size), range (variety), and nature (characteristics) (also known as a scope) following a systematic approach to map the available evidence (research) and gaps on a topic (Arksey et al, 2005; Peters et al, 2021; Tricco et al, 2018). Guidance is available through the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—Extension for Scoping Reviews (PRISMA (prismastatement.org).

We propose to conduct a scoping review of the published scientific literature on community-based brain health programs. Following the standard scoping review steps we will develop a protocol and review questions, identify the eligibility criteria, select and screen the sources, extract and chart the results, and write and publish the results.

Selected References for Scoping Reviews

Arksey & O'Malley (2005). Scoping studies: Towards a methodological framework. Int J Soc Res Methods, 8 (1), 19-32.

Peters et al (2021). Scoping reviews: Reinforcing and advancing the methodology and application. Syst Rev, 10 (263), 1-6.

Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. (2018). PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 169:467–473.

Selected Scoping Reviews Dr. Belza has Co-authored about Cognitive Health.

Friedman, D.B., Becofsky, K., Anderson, L.A., Bryant, L.L., Hunter, R.H., Ivey, S.L., **Belza**, B., Logsdon, R.G., Brannon, S., Vandenberg, A.E., & Lin, S.Y. (2015). Public perceptions about risk and protective factors for cognitive health and impairment: A review of the literature. <a href="International-Inte

McGough E, Lin S, **Belza** B, Becofsky K, Jones D, Liu M, Wilcox S, Logsdon R. (2017). A scoping review of physical performance outcome measures used in exercise interventions for older adults with Alzheimer's disease and related dementias. <u>Journal of Geriatric Physical Therapy</u>. Nov 28. doi: 10.1519/JPT.000000000000159.

Quinn K, Miyawaki C, Croff R, Vogel M, **Belza** B, Souza A, Liu M, Edwards V, Friedman D. (2020). Terms and Measures of Cognitive Aging and Cognitive Health: A Scoping Review. Research on Aging, 42(5-6) 174–185. DOI: 10.1177/0164027520911284

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors. Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Basia Belza

eRA COMMONS USER NAME (credential, e.g., agency login): BBELZA

POSITION TITLE: de Tornyay Endowed Professor in Healthy Aging

EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing,

include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Start Date MM/YYYY	Completion Date MM/YYYY	FIELD OF STUDY
Georgetown University, Wash., DC	BSN	06/1976	06/1978	Nursing
University of Virginia, Charlottesville, VA	MSN	09/1980	06/1982	Nursing
University of California, San Francisco, San Francisco, CA	PhD	09-1986	06/1991	Nursing

A. Personal Statement

I have a sustained record of scholarly activity directed toward improving the health of older adults through research, including the use of research results in practice. I am committed to improving our translational research efforts in the dissemination and implementation of evidence- and community-based health promotion programs for older adults. My work is informed by the RE-AIM framework.

I have consistently received research and training grant funding, both as a PI and as a co-investigator, from CDC and other agencies over the past 25 years. As a nurse scientist, I bring relevant expertise to this project including engagement with a Cognition in Primary Program, evaluation of evidence-based health promotion programs, a strong specialty-foci in gerontology, and a history of establishing and sustaining community-based partnerships.

I have served as principal investigator (PI) on three successful Centers for Disease Control and Prevention (CDC) Special Interest Projects (SIPs). As lead of the CDC-funded Coordinating Center for the Healthy Aging Research Network (HAN) (2009-2014) and in partnership with the CDC Healthy Aging Program, I oversaw the development and implementation of a national research and dissemination agenda related to the public health aspects of healthy aging. Under my leadership, HAN contributed to the improved understanding of the science of dissemination and implementation and provided technical assistance and support for the evidence-based health promotion movement. As lead of the CDC-funded Coordinating Center for the Healthy Brain Research Network (HBRN) (2014-2019) we established and advanced a public health research, translation, and dissemination agenda that promoted cognitive health, addressed cognitive impairment, and helped meet the needs of care partners. As PI of the SIP on Mall Walking (2015-2017), we evaluated the evidence on mall walking and conducted environmental assessments of malls and interviews with mall walkers and managers in which we identified strengths and opportunities with mall walking programs. Across these 3 SIPs I successfully built partnerships with community agencies, expanded our public health understanding of healthy aging and cognitive health, and disseminated findings to stakeholders.

As evidenced by my scholarly publications and presentations, I have contributed to improving our evaluation of cognition and management of dementia in clinical settings and long-term care communities, clarified the terms and measures used in the cognitive health space, supported the training of the next generation of cognitive health researchers, collaborated with community partners on innovative initiatives promoting cognitive health, and advocated for including voices of people living with dementia and their care partners in the development of our initiatives.

- A. Tang, W., Friedman, D. B., Kannaley, K., Davis, R. E., Wilcox, S., Levkoff, S. E., Hunter, R. H., Gibson, A., Logsdon, R. G., Irmiter, C., & Belza, B. (Epub April 2019). Experiences of caregivers by care recipient's health condition: A study of caregivers for Alzheimer's disease and related dementias versus other chronic conditions. Geriatric Nursing, 40 (2), 181-184.
- B. Quinn K, Miyawaki C, Croff R, Vogel M, Belza B, Souza A, Liu M, Edwards V, Friedman D. (2020). Terms and Measures of Cognitive Aging and Cognitive Health: A Scoping Review. Research on Aging, 42(5-6) 174–185. DOI: 10.1177/0164027520911284
- C. Croff, R, Tang W, Friedman D, Balbim G, Belza B (2021). Training the Next Generation of Aging and Cognitive Health Researchers. Gerontology and Geriatric Education.
- D. Renn B, Wool J, Belza B. (2021). A Typical Week with Mild Cognitive Impairment. The Gerontologist.
- E. Belza B, Kim B, Prophater L, Cameron S, Fazio S (2021). Organizational Dementia Care Coaching: Evaluating Acceptability and Feasibility. Poster presentation at Western Institute of Nursing, Online due to COVID-19.
- F. Fitzpatrick A, Gaster B, Raetz J, Zigman M, Belza B (2021). Dementia Care Practice: Supporting Communities to Deliver Quality Dementia Care. Podium presentation at the Alzheimer's Association International Conference. Online due to COVID.
- G. Belza B, Kim B, Prophater L, Cameron S, Fazio S. Dementia Care Coaching: A Pilot to Evaluate Acceptability and Feasibility in Care Communities. Accepted for poster presentation at The Gerontological Society of America 2021 Annual Scientific Meeting, Phoenix, Arizona. November 10, 2021.
- H. Zhai S; Kim B; Li J; Wi D; Chey S; Li G; Rungruangkonkit S; Belza B (2022). A cross-cultural/language qualitative study of perceptions and beliefs of memory loss and dementia among Korean, Samoan, Cambodian, and Chinese older adults. Journal of Gerontological Nursing. 48 (6), 40-47.
- I. Strayer A, Petrescu-Prahova M, Belza B, Herridge C, Zhou Y, Lafazia D. (2023). Implementation and Impact of a Dementia Friends Pilot. Dementia, 1-21.
- J. Webel A, Sadak T, Belza B, Denison P (2023). At-Home Exercise Programming: Including Voices of People Living With Dementia and Their Care Partners When Designing Interventions (guest editorial). Journal of Gerontological Nursing, 49 (1), 1-3.
- K. Wang Z, Belza B (2023). Is Every Meal a Message? Understanding the Eating Experience of Older Adults with Dementia Through Heideggerian Phenomenology. Journal of Gerontological Nursing, 49 (2), 3-4.

Relevant grants that I am currently playing a role are noted below:

Centers for Medicare and Medicaid Services (CMS), grant funded 04/21-09/23 Implementing Dementia Care Practice Recommendations in Montana State Assisted Living Communities Role: PI of Subcontract from the Alzheimer's Association

Centers for Disease Control and Prevention (CDC), grant funded 09/21 – 09/24 Evaluating alternative delivery models for arthritis-appropriate evidence-based physical activity and self-management interventions

Role: Co-investigator

Centers for Disease Control and Prevention (CDC), grant funded 09/22-09/24

Improving Cognitive Impairment Detection and Referral to Resources among Older Adults: Applying the KAER Model to Primary Care within a Health Care System

Role: Co-investigator

Donor Funded, grant funded 04/22-12/24

Implementing Dementia Care Practice Recommendations in Ohio State Assisted Living Communities Role: PI of Subcontract from the Alzheimer's Association

Centers for Disease Control and Prevention (CDC), grant funded 09/21 – 09/25 Health Promotion Research Center which partners with communities to conduct prevention research that promotes healthy aging and is incorporated into community practice. Role: Co-investigator

B. Positions, Scientific Appointments and Honors

Positions and Employment

1978 - 1980	Staff Nurse, Georgetown University Medical Center, Washington, DC
1982 - 1983	Clinical Instructor, School of Nursing, Georgetown University, Washington, DC
1983 - 1985	Clinical Educator, Clinical Center, National Institutes of Nursing, Bethesda, MD
1991- 1997	Assistant Professor, School of Nursing, University of Washington, Seattle, WA
1997- 2006	Associate Professor, School of Nursing, University of Washington, Seattle, WA
2006 - 2022	Aljoya Endowed Professor in Aging, School of Nursing, University of Washington, Seattle, WA
1999 - 2000	Vice-Chair, Dept of BNHI, School of Nursing, University of Washington, Seattle, WA
2007 - current	Adjunct Professor, School of Public Health, University of Washington, Seattle, WA
2007 - current	Professor, School of Nursing, University of Washington, Seattle, WA
2016 - 2017	Interim Assoc Dean for Academic Affairs, University of Washington, Seattle, WA
2018 - current	Director, de Tornyay Center for Healthy Aging, University of Washington, Seattle, WA

Other Experience and Professional Memberships

<u>Honors</u>	
2000	National Volunteer Service Citation, Arthritis Foundation, WA/AK Chapter
2003	Outstanding Volunteer, Arthritis Foundation, WA/AK Chapter
2005	Star Award, 40th Anniversary of the Association of Rheumatology Health Professions
2006	The Aljoya Endowed Professorship, School of Nursing
2008	President's Award, Association of Rheumatology Health Professions
2009	Fellow, American Academy of Nurses
2010	Distinguished Scholar Award , Association of Rheumatology Health Professions
2013	Distinguished Alumae Award, Santa Catalina High School
2015	UW Comotion Presidential Innovation Fellow Award, University of Washington
2016	APEX Award for Publication Excellence, APEX
2017	Western Academy of Nurses, Western Institute of Nurses
2018	APEX Award for Publication Excellence, Connecting with AAPI about Dementia
2020	Fellow, Gerontological Society of America
2020	Anna Shannon Mentorship Award, Western Institute of Nursing
2023	The de Tornyay Endowed Professorship in Healthy Aging

C. Contributions to Science

- 1. As an investigator at the University of Washington (UW) Health Promotion Research Center I have been deeply committed to and involved with another evidence-based program called EnhanceFitness (EF) for over 20 years. I have over 14 data-based, scholarly publications about EF. Through my initial work with EF I helped it get approved for use by people with arthritis and as such the Arthritis Program at CDC adopted it. I have built partnerships with colleagues and institutions across the country such as the Y-USA and others who research and disseminate EF and many of whom are members of the consortium at the Self-Management Resource Center. Additionally, I have co-authored additional publications on topics related to evidence-based programs.
 - A. Belza, B., Shumway-Cook, A., Phelan, E., Williams, B., Snyder, S., LoGerfo, J. (2006). The effects of a community-based exercise program on function and health in older adults: The EnhanceFitness Program. Journal of Applied Gerontology, 25 (4), 291-306.
 - B. Gillette DB, Petrescu-Prahova M, Herting JR, Belza B. A Pilot Study of Determinants of Ongoing Participation in EnhanceFitness: A Community-Based Group Exercise Program for Older Adults. J Geriatr Phys Ther. 2015 Oct-Dec;38(4):194-201. PubMed PMID: <u>25695473</u>; PubMed Central PMCID: <u>PMC4540700</u>.

- C. Petrescu-Prahova M, Belza B, Kohn M, Miyawaki C. Implementation and Maintenance of a Community-Based Older Adult Physical Activity Program. The Gerontologist. 2016 Aug;56(4):677-86. PubMed PMID: 26035891; PubMed Central PMCID: PMC6282690.
- D. Petrescu-Prahova MG, Eagen TJ, Fishleder SL, Belza B. Enhance®Fitness Dissemination and Implementation,: 2010-2015: A Scoping Review. Am J Prev Med. 2017 Mar;52(3 Suppl 3):S295-S299. PubMed PMID: 28215384.
- E. Miyawaki CE, Belza B, Kohn MJ, Petrescu-Prahova M. Champions of an Older Adult Exercise Program: Believers, Promoters, and Recruiters. J Appl Gerontol. 2018 Jun;37(6):728-744. PubMed PMID: 27122301.
- F. Pascoe, K.M., Petrescu-Prahova, M., Steinman, L., Bacci, J., Mahorter, S., Belza, B., Weiner, B.J. (2021). Exploring the Impact of Workforce Turnover on the Sustainability of Evidence-Based Programs: A Scoping Review. Implementation Research and Practice, 2, 1-23.
- G. Petrescu-Prahova M, Harris J, Leroux B, Kohn M, Kava C, Zeliadt S, Steinman L, Belza B, Gakhar M, Hannon P. (2022). Clinical-Community Linkages as a Strategy for Increasing Evidence-Based Program Reach: Results of the PT-REFER Randomized Controlled Trial with Older Adults and YMCA Associations. Contemporary Clinical Trials Communications.
- 2. I developed the Multidimensional Assessment of Fatigue (MAF) scale for rheumatoid arthritis for my dissertation in 1991. Since the publication of the scale in Nursing Research (Belza et al., 1993) the MAF has had world-wide dissemination and uptake and been translated in 40+ languages and been used and published in 100 research studies (Belza et al., 2018). My 1993 publication in Nursing Research is in the top 50 most frequently cited nursing publications (Wong et al., 2013). This scale has helped improve our measurement, understanding and treatment of fatigue in chronic diseases.
 - A. Belza B, Miyawaki CE, Liu M, Aree-Ue S, Fessel M, Minott KR, Zhang X. A Systematic Review of Studies Using the Multidimensional Assessment of Fatigue Scale. J Nurs Meas. 2018 Apr 1;26(1):36-75. PubMed PMID: 29724278.
 - B. Belza BL. Comparison of self-reported fatigue in rheumatoid arthritis and controls. J Rheumatol. 1995 Apr;22(4):639-43. PubMed PMID: <u>7791155</u>.
 - C. Belza B. The impact of fatigue on exercise performance. Arthritis Care Res. 1994 Dec;7(4):176-80. PubMed PMID: 7734475.
 - D. Belza BL, Henke CJ, Yelin EH, Epstein WV, Gilliss CL. Correlates of fatigue in older adults with rheumatoid arthritis. Nurs Res. 1993 Mar-Apr;42(2):93-9. PubMed PMID: 8455994.
- 3. I have built and sustained two inaugural CDC-funded thematic networks. First, I led the Coordinating Center for the Healthy Aging Research Network (HAN) (2008-2014). The HAN has been used as a model network for other Networks due to being a highly productive and collaborative cross-sector and multidisciplinary network. Second, I led the Coordinating Center for the Healthy Brain Research Network (HBRN) (2014-2019) which was charged with developing a research and translation agenda and implementing actions in the Alzheimer's Disease Road Map
 - A. Belza B, Altpeter M, Smith ML, Ory MG. The Healthy Aging Research Network: Modeling Collaboration for Community Impact. Am J Prev Med. 2017 Mar;52(3 Suppl 3):S228-S232. PubMed PMID: 28215370.
 - B. Ory MG, Altpeter M, Belza B, Helduser J, Zhang C, Smith ML. Perceptions about community applications of RE-AIM in the promotion of evidence-based programs for older adults. Eval Health Prof. 2015 Mar;38(1):15-20. PubMed PMID: 25015082.
 - C. Smith ML, Ory MG, Ahn S, Belza B, Mingo CA, Towne SD Jr, Altpeter M. Reaching diverse participants utilizing a diverse delivery infrastructure: a replication study. Front Public Health. 2015;3:77. PubMed PMID: 25964949.
 - D. Smith ML, Ory MG, Belza B, Altpeter M. Personal and delivery site characteristics associated with intervention dosage in an evidence-based fall risk reduction program for older adults. Transl Behav Med. 2012 Jun;2(2):188-98. PubMed PMID: 24073111; PubMed Central PMCID: PMC3717890.
- 4. Under my leadership, our multidisciplinary and multi-state team built the science supporting the evidence for mall walking for older adults. Through CDC funding we: 1) published an extensive scoping review of the literature on mall walking, 2) interviewed over 50+ mall walkers, mall managers, mall walking program directors, 3) and completed environmental audits in 10 malls and non-mall walking areas in 5 states. We

developed and published an award-winning Mall Walking: A Program Resource Guide. This work is relevant for this proposal for as it demonstrates my ability to build evidence for a community-based program, collaborate with community partners, develop an award-winning resource guide, and effectively disseminate findings.

- A. Belza B, Miyawaki CE, Allen P, King DK, Marquez DX, Jones DL, Janicek S, Rosenberg D, Brown DR. Building Community: Stakeholder Perspectives on Walking in Malls and Other Venues. J Aging Phys Act. 2017 Oct 1;25(4):510-524. PubMed PMID: 28095085.
- B. King DK, Allen P, Jones DL, Marquez DX, Brown DR, Rosenberg D, Janicek S, Allen L, Belza B. Safe, Affordable, Convenient: Environmental Features of Malls and Other Public Spaces Used by Older Adults for Walking. J Phys Act Health. 2016 Mar;13(3):289-95. PubMed PMID: <u>26181907</u>; PubMed Central PMCID: <u>PMC4927000</u>.
- C. Farren L, Belza B, Allen P, Brolliar S, Brown DR, Cormier ML, Janicek S, Jones DL, King DK, Marquez DX, Rosenberg DE. Mall Walking Program Environments, Features, and Participants: A Scoping Review. Prev Chronic Dis. 2015 Aug 13;12:E129. PubMed PMID: 26270743; PubMed Central PMCID: PMC4552141.

Complete List of Published Work in MyBibliography:

https://www.ncbi.nlm.nih.gov/sites/myncbi/1tMJ24hLl3bQa/bibliography/47766598/public/?sort=date&direction =ascending

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors. Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Boeun Kim

eRA COMMONS USER NAME (credential, e.g., agency login): bkim101

POSITION TITLE: Postdoctoral fellow

EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Ewha Womans University, Seoul, South Korea	BSN	02/2008	Nursing
Ewha Womans University, Seoul, South Korea	MSN	08/2015	Nursing
University of Washington, Seattle, USA	MPH	03/2022	Epidemiology
University of Washington, Seattle, USA	PhD	08/2021	Nursing
Johns Hopkins University, Baltimore, USA	Postdoctoral	09/2024 (Expected)	Nursing

A. Personal Statement

I am a postdoctoral fellow funded by the National Institute on Aging (NIA) project of "Reducing racial disparities in Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD): Addressing structural discrimination and resilience". I worked as a registered nurse at Samsung Medical Cancer Center from Mar, 2008 to Feb, 2012 and at Samsung Medical Emergency Room from Sep, 2012 to Mar, 2014. I started my academic career in 2016 and earned MPH degree in Epidemiology and PhD in Nursing along with a statistical concentration program. My belief in health equity shaped my academic journey which I shared in a published editorial at the Journal of Gerontological Nursing. My research has focused on individual and environmental factors related to older adults' health, particularly cognitive function. In my dissertation, I examined associations of objective and subjective walkable neighborhood factors with cognition in older adults as well as mediating role of walking on the associations. I measured objective walkable neighborhood using geographic information systems (GIS). I found that walking explained the association between subjective neighborhood walkability and cognitive function but not the relationship between objective neighborhood walkability and cognitive function. In my thesis, I investigated if exposure to air pollution was associated with physical function decline among older adults. Furthermore, I have been actively involved in several research studies that involve interfacing with diverse community agencies locally, regionally, and nationally. I have worked with multidisciplinary research teams and have had responsibilities for data management and analysis. I have collaborated with Dr. Belza for 8 years on research projects. I have informally taught others about REDCap, qualitative analysis, and grant writing.

Recently completed projects that I would like to highlight include: Hester McLaws Dissertation Grant, School of Nursing, University of Washington Kim (PI) 02/2020 - 08/2021

Neighborhood attributes and cognitive function in older adults

de Tornyay Center Healthy Aging research grant, School of Nursing, University of Washington Kim (PI)

11/2019 - 10/2020

Walkable neighborhoods and cognitive health in older adults

Papers particularly relevant to the proposed project include:

- a. **Kim B**, Belza B. Toward an Equitable Society for Every Generation. *J Gerontol Nurs*. 2017;43(11):2-4. doi:10.3928/00989134-20171012-01
- b. **Kim B**, Barrington WE, Dobra A, Rosenberg D, Hurvitz P, Belza B. Mediating role of walking between perceived and objective walkability and cognitive function in older adults. *Health Place*. 2023;79:102943. doi:10.1016/j.healthplace.2022.102943
- c. **Kim B**, Rosenberg D, Dobra A, Barrington WE, Hurvitz P, Belza B. Association of perceived neighborhood environments with cognitive function in older adults. (In press)
- d. Greenwood-Hickman MA, Walker R, Bellettiere J, LaCroix AZ, **Kim B** et al. Associations Between Perceived Neighborhood Walkability and Device-Based Physical Activity and Sedentary Behavior Patterns in Older Adults. *J Aging Phys Act.* 2022;30(1):98-106. doi:10.1123/japa.2020-0387
- e. **Kim B**, Hajat A, Adam C, Kaufman JD, Leary CS, Semmens E, Fitzpatrick A. (2022, September). Associations between air pollution and gait speed in older adults. Poster virtually presented at the International Society for Environmental Epidemiology Conference, Athens, Greece, September 18-21, 2022.

B. Positions, Scientific Appointments, and Honors

Positions and Scientific Appointments

05/2019 - Present	Research Coordinator. Implementing the Alzheimer's Association Dementia Care
	Practice Recommendations in Care Communities. Funded by Civil Money Penalty Funds
	and Alzheimer's Association.
06/2019 - 03/2021	Co-investigator. Asian Counseling and Referral Service Dementia Project.
03/2019 - 08/2019	Co-investigator. Blogs Analysis on Engaging with Aging Project.
06/2018 - 03/2019	Project Manager. Outcomes of Early-Stage Memory Loss Interventions: A Systematic
	Review.

Awards and Honors

Awarus anu monors	
06/2021	de Tornyay Center Healthy Aging PhD Pathways to Healthy Aging award
04/2019	Best Gerontology Theory Presentation, The Western Institute of
	Nursing Gerontology Special Interest Group, San Diego, CA
06/2020	King County Nurse Association Scholarship
09/2019, 09/2018	Scholarship, Pfeiffer Endowed Fund/Goldsbury Memorial Endowment Fund,
	School of Nursing, University of Washington
08/2019	Healthy Brain Research Network and the de Tornyay Center Travel
	Scholarship
02/2019	2019 Travel Scholarships for Health Brain Research Network Scholars,
	Alzheimer's Association
09/2017	Scholarship, Pfeiffer Endowed Fund, School of Nursing, University of
	Washington
09/2016	Top Scholar Award and a School of Nursing Scholarship, School of Nursing,
	University of Washington
03/2015, 09/2014	Research Assistant Scholarship, Ewha Womans University
03/2014, 09/2013	Honors Scholarship, Ewha Womans University
09/2007, 03/2007	Honors Scholarship, Ewha Womans University
09/2006	Win Er Semeste Scholarship, Ewha Womas University
09/2006, 03/2006, 09/2005	Honors Scholarship, Ewha Womans University

C. Contributions to Science

1. Cognitive Health among Older Adults: I have joined multiple projects to improve cognitive health or relevant factors. With other research team members, we found differential perceptions and beliefs of memory loss and dementia among minoritized groups to contribute to developing a tailored intervention program to promote cognitive health. Additionally, the Sharing History through Active Reminiscence and Photo-imagery (SHARP) project, developed by Dr. Raina Croff at Oregon Health & Science University, was conducted in a historically Black neighborhood but undergoing rapid gentrification in Seattle. The SHARP project is a multimodal walking program, and the program was delivered via a smartphone application displaying GPS-mapped routes in the neighborhood. Community members or their representatives involved in the project from the planning phase to the end. I wrote a grant application for community partners to secure funding from Seattle Department of Neighborhoods to implement the program. I also have analyzed the data obtained from the project. Colleagues and I are working on a manuscript to publish the findings from the SHARP project. Lastly, I have also worked with Alzheimer's Association for 4 years to implement the Dementia Care Practice Recommendations (DCPR) program through coaching. The DCPR program completed pilot studies in OH, WA, and MT. The clusterrandomized trial is ongoing and is recruiting 40 assisted living and 40 nursing homes in OH. As a researcher, I am managing the randomization, data collection using REDCap and statistical evaluation of outcomes. The manuscript of findings from pilot studies is submitted and under review.

Recently completed projects that I would like to highlight include:

Neighborhood Matching Fund, Seattle Department of Neighborhoods

Kim (Grant writer, PI: Community group).

Honoring community health and history (Seattle Sharing History through Active Reminiscence and Photo imagery project

11/2021 – 10/2022

Papers that I would like to highlight include:

- a. Zhai S, **Kim B**, Li J, et al. Perceptions and Beliefs of Memory Loss and Dementia Among Korean, Samoan, Cambodian, and Chinese Older Adults: A Cross-Cultural Qualitative Study. *J Gerontol Nurs*. 2022;48(6):40-48. doi:10.3928/00989134-20220506-03
- b. Zaslavsky O, Su Y, Kim B, Roopsawang I, Wu KC, Renn BN. Behavior Change Factors and Retention in Dietary Interventions for Older Adults: A Scoping Review. *Gerontologist*. 2022;62(9):e534-e554. doi:10.1093/geront/gnab133
- c. **Kim B**, Croff R, Kaluna L, Becker M, Winston K, Belza B. (2022, April) Reminiscence on mood, cognition, and social engagement: A scoping review. Poster presented at the Western Institute of Nursing's 55th Annual Communicating Nursing Research Conference, Portland, OR, April 6-9, 2022.
- d. Belza, B., **Kim, B.**, Prophater, L., Cameron, S., & Fazio, S. (2021, November). Dementia Care Coaching: A Pilot to Evaluate Acceptability and Feasibility in Care Communities. Poster presented at The Gerontological Society of America 2021 Annual Scientific Meeting, Phoenix, Arizona. November 10-14, 2021.
- 2. Structural and Social Determinants of Health in Older Adults: My work has been focused on social determinants that can contribute to disparities in cognitive health. I participated manuscripts as a co-author: a review paper on "The structural and social determinants of Alzheimer's Disease and Related Dementias" and a cross-sectional study of "Does Supplemental Nutrition Assistance Program access address racial disparities in food insecurity". I examined food insecurity in relation to cognitive function and I found that reported food insecurity was associated with decline in executive function over time among older adults. I am leading projects to evaluate the impacts of food environment on cognitive function. I am also working on another manuscript as a second author to measure structural socioeconomic status across the life span and their impacts on cognitive function among Black adults aged 50+, which is under review.
 - a. Adkins-Jackson PB, George KM, Besser LM, Hyun J, Lamar M, Hill-Jarrett TG, Bubu OM, Flatt JD, Heyn PC, Cicero EC, Zarina Kraal A, Pushpalata Zanwar P, Peterson R, **Kim B**, et al. The structural and social determinants of Alzheimer's disease related dementias [published online ahead of print, 2023 Apr 19]. *Alzheimers Dement*. 2023;10.1002/alz.13027. doi:10.1002/alz.13027

- b. Samuel LJ, Crews DC, Swenor BK, Zhu J, Stuart EA, Szanton SL, Kim B, Dwivedi P, Li Q, Reed NS, Thorpe RJ. Supplemental Nutrition Assistance Program Access and Racial Disparities in Food Insecurity. (In Press)
- c. **Kim B**, Samuel LJ, Thorpe RJ Jr, Crews DC, Szanton SL. Food Insecurity and Cognitive Trajectories in Community-Dwelling Medicare Beneficiaries 65 Years and Older. *JAMA Netw Open*. 2023;6(3):e234674. doi:10.1001/jamanetworkopen.2023.4674

Complete List of Published Work in Google scholar:

https://scholar.google.com/citations?hl=en&user=NeT2N5YAAAAJ

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors. Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Pike, Kenneth C.

eRA COMMONS USER NAME (credential, e.g., agency login): kenpike

POSITION TITLE: Research Scientist

EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
University of Washington, Seattle, WA	BA	06/1980	Sociology/Chemistry
University of Washington, Seattle, WA	MA	06/1984	Sociology
University of Washington, Seattle, WA	PhD	07/1996	Sociology

A. Personal Statement

My role as a contributor on Drs. Belza's proposed study is methodological and statistical analysis expertise, consistent with my education and experience. I have over 25 years of NIH-funded clinical research experience as a research scientist and statistical consultant. I have collaborated in a wide range of health-related studies, including, intervention research in the areas of Alzheimer's disease outcome studies, adolescent health/mental health, women substance abuse users and longitudinal studies in at-risk youth, COPD patients, adolescent sleep studies, and hospice caregivers. I have extensive experience working with large, longitudinal studies, experience with managing complex data structures and expertise in designing REDCap databases and surveys. I will provide support to Dr. Belza in data analysis for this study. My methodological interests throughout my career have kept me on the forefront of statistical procedures including multilevel longitudinal mixed effects linear regression models proposed in this study as well as expertise in structural equation modeling, latent class analysis growth curve modeling, intent-to-treat designs, multiple imputation procedures for the management of missing data, and alternative strategies for analyzing data that do not meet underlying statistical assumptions. As a research scientist, I have collaborated with multiple research groups and graduate students in the UW School of Nursing and the Office for Nursing Research and provided guidance on longitudinal designs and complex methodological analysis. I have worked with Dr. Belza on previous occasions and I look forward to collaborating on this grant.

Ongoing and recently completed projects that I would like to highlight include:

R21 AG082537 Oliveira (PI) 4/16/2023-12/31/2024

The Influence of Habitual Physical Activity and Diet in the Development of Sarcopenia Among Older Adults With HIV

Role: Collaborating Investigator and Statistician

R21/R33 AT009932 Price, Merrill (MPIs) 7/1/18-4/30/24

Mindful Body Awareness Training as an Adjunct to Medication Assisted Treatment for Opioid Use Disorder Role: Research Scientist/Data Analyst

Arnold Ventures Grant

Kohler, Cox-North, Basu (MPIs)

7/1/22-ongoing

Progress towards Hepatitis C Elimination in Washington State

Role: Research Scientist/Data Analyst

1K23HL144910 - 01A1

Blakeney (PI)

8/01/2021-07/30/2026

Implementation and Sustainment of Team-Based Practice Transformation to Improve Heart Failure Care and

Outcomes

Role: Research Scientist/Data Analyst

R01 AG053221

Vitiello, McCurry, Von Korff (MPIs)

7/1/16-6/30/21

Efficacy of Scalable CBT for Insomnia in Older Adults with Osteoarthritis Pain

Role: Research Scientist

Citations:

- 1. Teri L, Logsdon RG, McCurry SM, **Pike KC**, McGough EL. Translating an Evidence-based Multicomponent Intervention for Older Adults With Dementia and Caregivers. *Gerontologist*. 2020; 60(3):548-557. doi: 10.1093/geront/gny122.
- McCurry SM, Logsdon RG, Pike KC, LaFazia DM, Teri L. Training Area Agencies on Aging Case Managers to Improve Physical Function, Mood, and Behavior in Persons With Dementia and Caregivers: Examples from the RDAD-Northwest Study. *J Gerontol Soc Work*. 2018 Jan;61(1):45-60. PMCID: PMC5939562.
- 3. Yohannes AM, Kohen R, Nguyen HQ, **Pike KC**, Borson S & Fan VS (2021) Serotonin transporter gene polymorphisms and depressive symptoms in patients with chronic obstructive pulmonary disease, *Expert Review of Respiratory Medicine*, 15:5, 681-687, DOI: 10.1080/17476348.2021.1865159
- 4. Price CJ, Thompson EA, Crowell S, **Pike K**. Longitudinal effects of interoceptive awareness training through mindful awareness in body-oriented therapy (MABT) as an adjunct to women's substance use disorder treatment: A randomized controlled trial. *Drug Alcohol Depend*. 2019 May 1;198:140-149. PMCID: PMC6467707.

B. Positions, Scientific Appointments, and Honors

Positions and Scientific Appointments

2018 – Present	Research Scientist, "Mindful Body Awareness Training as an Adjunct to Medication Assisted Treatment for Opioid Use Disorder Study, Department of Biobehavioral Nursing and Health Informatics, University of Washington, Seattle, WA
2016 – 2021	Evaluation Director, "Center for Innovation in Sleep Self-Management", School of Nursing, University of Washington, Seattle, WA
2014 - Present	Research Consultant, Office of Nursing Research, University of Washington, Seattle, WA
2014 – 2018	Research Scientist, "CASCADE Study", Department of Biobehavioral Nursing and Health

	Informatics, University of Washington, Seattle, WA
2011 – 2017	Research Scientist, "Hospice Caregiver Study", Department of Biobehavioral Nursing and Health Systems, University of Washington, Seattle, WA
2005 – 2018	Research Scientist, "Northwest Research Group on Aging", Department of Psychosocial and Community Health Nursing, University of Washington, Seattle, WA
1998 – 2008	Research Scientist, "Reconnecting at Risk Youth" research project", Department of Psychosocial and Community Health Nursing, University of Washington, Seattle, WA
1993 – 1997	Research Associate, "Self-Management Therapy Following Sudden Cardiac Arrest" research project, Department of Biobehavioral Nursing and Health Systems, School of Nursing, University of Washington, Seattle, WA
1990 – 1993	Research Associate, "Biobehavioral Nursing Intervention with Hypertension" research project, Department of Psychosocial Nursing, University of Washington, Seattle, WA
1988 – 1990	Pre-Doctoral Research Assistant, "Body/Behavioral Experiences: Recovery from Alcoholism" research project, Department of Psychosocial Nursing, University of Washington, Seattle, WA
1985 – 1987	Research Assistant, "Reactions to Harmdoing" research project, Department of Sociology, University of Washington, Seattle, WA
1984 – 1985	Instructor, Department of Sociology, University of Washington, Seattle, WA

C. Contributions to Science

- 1. Youth Suicide Prevention: These papers come out of a collaboration with an interdisciplinary group of prevention scientists developing and evaluating youth suicide prevention programs. I participated as a methodologist, data manager and analyst in these prevention programs.
 - a. Kim J, Walsh E, **Pike K**, Thompson EA. Cyberbullying and Victimization and Youth Suicide Risk: The Buffering Effects of School Connectedness. *J Sch Nurs*. 2019 Jan 21;doi: 10.1177/1059840518824395.
 - b. Hooven C, **Pike K**, Walsh E. Parents of older at-risk youth: a retention challenge for preventive intervention. *J Prim Prev*.2013 Dec;34(6):423-38.
 - c. Hooven C, Walsh E, **Pike KC**, Herting JR. Promoting CARE: including parents in youth suicide prevention. *Fam Community Health*. 2012 Jul-Sep;35(3):225-35. PMCID: PMC3616767.
 - d. Thompson EA, Eggert LL, Randell BP, **Pike KC**. Evaluation of indicated suicide risk prevention approaches for potential high school dropouts. *Am J Public Health*. 2001 May;91(5):742-52. PMCID: PMC1446664.
- 2. Development and testing of non-pharmacological interventions to treat dementia-related neuropsychiatric symptoms. These studies are representative of my collaboration with the University of Washington's Research Group on Aging since 2005 as an analyst and data manager. These studies emphasize training caregivers to use behavioral and physical activity strategies to improve mood and reduce behavior challenges in persons with dementia.
 - a. Teri L, Logsdon RG, McCurry SM, **Pike KC**, McGough EL. Translating an Evidence-based Multicomponent Intervention for Older Adults With Dementia and Caregivers. *Gerontologist*. 2018 Oct 9. doi: 10.1093/geront/gny122.
 - b. McCurry SM, Logsdon RG, Pike KC, LaFazia DM, Teri L. Training Area Agencies on Aging Case Managers to Improve Physical Function, Mood, and Behavior in Persons With Dementia and Caregivers: Examples from the RDAD-Northwest Study. *J Gerontol Soc Work*. 2018 Jan;61(1):45-60. PMCID: PMC5939562.
 - c. McCurry SM, Logsdon RG, Mead J, **Pike KC**, La Fazia DM, Stevens L, Teri L. Adopting Evidence-Based Caregiver Training Programs in the Real World: Outcomes and Lessons Learned From the STAR-C Oregon Translation Study. *J Appl Gerontol*. 2017 May;36(5):519-536.
 - d. McCurry SM, **Pike KC**, Vitiello MV, Logsdon RG, Larson EB, Teri L. Increasing walking and bright light exposure to improve sleep in community-dwelling persons with Alzheimer's disease: results of a randomized, controlled trial. *J Am Geriatr Soc.* 2011 Aug;59(8):1393-402. PMCID: PMC3158242.
- 3. Descriptive studies of informal hospice caregivers. I am a co-investigator with the Hospice Caregiving Research Network, an interdisciplinary team designing and testing interventions to

support caregivers. I am currently the data manager and analyst on the largest study of informal hospice caregivers funded by the NIH.

- a. Demiris G, Oliver DP, Washington K, **Pike K**. A Problem-Solving Intervention for Hospice Family Caregivers: A Randomized Clinical Trial. *J Am Geriatr Soc.* 2019 Apr 4;. doi: 10.1111/jgs.15894.
- b. Chi NC, Demiris G, **Pike KC**, Washington K, Parker Oliver D. Exploring the Challenges that Family Caregivers Faced When Caring for Hospice Patients with Heart Failure. *J Soc Work End Life Palliat Care*. 2018 Apr-Sep;14(2-3):162-176. PMCID: PMC6274608.
- c. Tarter R, Demiris G, **Pike K**, Washington K, Parker Oliver D. Pain in Hospice Patients With Dementia: The Informal Caregiver Experience. *Am J Alzheimers Dis Other Demen*. 2016 Sep;31(6):524-9. PMCID: PMC4982799.
- d. Washington KT, Demiris G, **Pike KC**, Kruse RL, Oliver DP. Anxiety among informal hospice caregivers: an exploratory study. *Palliat Support Care*. 2015 Jun;13(3):567-73. PMCID: PMC4133335.

Complete List of Published Work in MyBibliography:

https://www.ncbi.nlm.nih.gov/myncbi/1t1blplwgzkAy/bibliography/public/



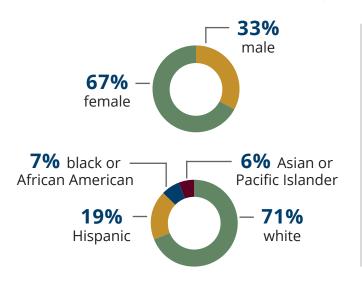
Reducing Social Isolation and Loneliness among Older Adults

The purpose of this research brief is to share results about a pre-COVID-19 study about social isolation and loneliness in Washington state. We sought information on social isolation and loneliness from older adults. The participants were recruited from seven clinical and community sites in Washington state.

SURVEY PARTICIPANTS



A total of 116 OLDER ADULTS, with ages ranging from 60 TO 101 YEARS.





40%

lived with a spouse or partner



75%

reported using a computer or smartphone in the previous two weeks



25% did not drive

RISKS FOR ISOLATION & LONELINESS



40-50% OF PARTICIPANTS

- Felt isolated from others (often or some of the time)
- Felt no one really knew them well (often or some of the time)
- Did not often feel part of a friend group
- Worried about being by themselves (often or some of the time)
- Could not often find companionship when they want it
- Missed having people around them



1 IN 5 PARTICIPANTS

- Avoided socializing because of difficulties understanding conversations
- Did not have the desired amount of contact with people they feel close to and can trust
- Were not content with their friendships and relationships

IN THE PREVIOUS MONTH **BEFORE TAKING THE SURVEY**



25% had a negative change in their health



had an emotional loss (e.g., death of a family member or friend)

IN THE PREVIOUS TWO WEEKS **BEFORE TAKING THE SURVEY**

14%

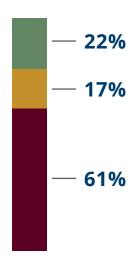
reported no face-to-face, telephone, or written/email/text contact with family members or friends

34%

did not participate in organizations such as social clubs, residents groups, or committees

55%

did not participate in religious groups



61%

of participants scored as high risk on the 13-item **Upstream Social Isolation Risk** Screener (U-SIRS)

IMPROVING CONNECTIVITY AMONG OLDER ADULTS

Take time to listen to older adults. Even if an older adult doesn't have a large group of family or friends, it only takes one person to make them feel valued, connected, and supported.

Encourage older adults to be open to new activities and new people. Identifying common interests can form bonds, create purpose, and develop positive relationships.

Identify ways to introduce meaningful interactions in different settings. Consider telephonic and internet-based services and programs that bring people together.

Consider these resources for getting connected at safe distances during COVID-19:

- Administration for Community Living: https://acl.gov/COVID-19
- National Council on Aging: https://www.ncoa.org/covid-19-resources-for-professionals
- AARP Foundation: https://connect2affect.org/

ACKNOWLEDGEMENTS

This study was a joint collaborative with funding from the AARP Foundation. We thank and acknowledge the support of our partners.

Iora Primary Care Jefferson Healthcare Northshore YMCA

Ida Culver House Broadview Lake City Seniors (Sound Generations)

Sea Mar Community Health Centers

Renton Senior Center













Concept Paper Accelerating Brain Health Conversations Through Community Coalitions

In their Stanford Social Innovation Review article, Kania and Kramer note that "large-scale social change requires broad cross-sector coordination, yet the social sector remains focused on the isolated intervention of individual organizations." The authors go on to describe large-scale projects where diverse groups came together to solve complex issues. For example, they described how:

- The Elizabeth River Project engaged over 100 diverse agencies and organizations to restore and conserve over 1,000 acres of watershed and
- An associate professor from Tuffs University led a diverse group of government officials, educators, businesses, nonprofits, and citizens in combating obesity at an elementary school in Somerville, Massachusetts.

These are just two examples of how, through cross-section collaboration, successful and meaningful change is possible.

Our colleagues at the Ohio Council for Cognitive Health (OCFCH) also exemplify the theory of collective impact in their statewide implementation of the Dementia Friends program. Specifically, these innovative leaders developed sector-specific resources for veterans, transportation providers, hospitals, libraries, airports, incarcerated settings, first responders, legal and financial service providers, care providers for people with intellectual and developmental disabilities, faith communities, and more. By doing so, they highlighted the relative advantage of the Dementia Friends program to each of these unique settings and facilitated broad uptake of the program.

OCFCH is now positioned as the lead organization to implement Dementia Friendly Communities in Ohio and seeks to charge each community planning to seek recognition as Dementia Friendly to incorporate the GSA KAER Toolkit for Primary Care Teams (i.e., KAER Toolkit for Brain Health) into their communitywide efforts.

In recognition of this incredible opportunity to engage a variety of sectors in conversations around the importance of actively promoting brain health and early detection and diagnosis of cognitive impairment, *The Gerontological Society of America (GSA) recommends development of sector-specific resources to support the integration of the KAER Toolkit into Dementia Friendly Community program development.* The goal of these resources would be to elevate the importance of brain health and early detection of cognitive impairment and the need to engage in brain health conversations across a wide variety of sectors in a given community.

GSA would collaborate with the OCFCH to develop the sector-specific resources which would be made freely available on the GSA website, geron.org, for use in the Ohio statewide implementation of Dementia Friendly Communities and by any other interested party. Additionally, we would seek to collect feedback about these sector-specific tools and the GSA KAER Toolkit from entities using them in their Dementia Friendly Community program development to allow for further enhancement of the resources.