



NIH-Funded CBPR: Self-Reported Community Partner and Investigator Perspectives

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Abstract

The community-based participatory research (CBPR) approach across health contexts has matured greatly over the last 20 years. Though contributions to the literature on the development and effectiveness of CBPR interventions have grown, the number of publications on the function and evaluation of actual community-research partnerships has not kept pace. To help address that gap, we searched National Institutes of Health archival data and identified a set of 489 CBPR projects including collaboration-building, exploratory/pilot, research, and program project grants. We found community partner contact information commonly was absent from grant records and contacted principal investigators (PIs) for community-partner contact information. Subsequently, we built upon established measures to ask principal investigators and community partners for their perceptions of participation in NIH-funded CBPR projects. Many principal investigators and community partners reported existing collaborations—between academicians and community organizations as well as among community organizations. Partners tended to agree on the appropriateness of funding levels to accomplish projects and on the community partners' ability to recruit and retain participants, collect data, and implement interventions. Partners differed in perceptions of participation in research design, data analyses, manuscript and presentation production, and dissemination of findings. Suggestions include collection of lead community partner information without undue burden and increased standard education and involvement of community organizations in research vocabulary and practices.

Keywords Community-based participatory research · Partner perspectives · Research perspectives · NIH portfolio

Introduction

The field of community-based participatory research (CBPR) has burgeoned since Barbara Israel et al. [1] first articulated a set of principles to promote active community

involvement in all phases of health research, from problem articulation, through study design, data collection and analysis, and dissemination of results, within a collaborative relationship that endures beyond the scope of any individual research project [2–4]. Beginning in the mid-1990s, the Institutes, Centers, and Offices (ICOs) of the National Institutes of Health (NIH) funded a series of CBPR research and training grants through targeted funding opportunities, investigator-initiated projects, and publications [5–9].

In the early 2000s, NIH's Office of Behavioral and Social Sciences Research (OBSSR) promoted CBPR as a strategy to develop, implement, evaluate, and disseminate community intervention research. For example, OBSSR coordinated the development of CBPR-specific funding opportunity announcements (FOAs), "to support research on health promotion, disease prevention, and health disparities that is conducted jointly by communities and researchers [10]." Federal partners on these FOAs included nine NIH ICOs, the Centers for Disease Control and Prevention, and the Agency for Healthcare Research and Quality. OBSSR

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coordinated CBPR FOAs between 2004 and 2013, provided technical assistance workshops and other training activities, and funded a short course (R25) on CBPR [11]. By 2018, all 24 NIH ICOs that fund and manage research projects hold CBPR projects. Though there was no single trans-NIH CBPR initiative, there has been substantive agency effort and investment in this regard.

We saw a need to understand the experiences of researchers and community members to understand whether and how they value this approach. Literature reviews in CBPR are plentiful; e.g., [2–4, 12] some CBPR reviews suggest that there is insufficient literature on the organizational capacities associated with ongoing successful CBPR partnerships [3–12]. To help resolve that disparity, we proposed two research questions:

- RQ1: What are the perceptions of researchers who have conducted NIH-funded CBPR projects?
- RQ2: What are the perceptions of community members who have been partners in NIH-funded CBPR projects?

More specifically, perceptions of the following were assessed: (1) prior history of collaboration between researchers and community members, (2) funding sufficiency, (3) prior history of collaborations among community organizations, (4) researcher views of community engagement, and (5) community partner views of community engagement.

Design

To identify a set of investigators and community partners associated with NIH-funded CBPR research projects, we began by identifying CBPR-related NIH grants via two strategies. First, grants associated with 15 CBPR-specific Funding Opportunity Announcements (FOAs) and a subset of 8 reissued FOAs were captured. Second, we searched NIH archival data (e.g., NIH RePORTER <https://projectreporter.nih.gov/>). We searched the entire database for all grants active between fiscal years 2004 and 2013 using the text search option with keywords *community based participatory research* and *CBPR* in the project title or the abstract by exact or non-exact match. Upon generating that list, we reviewed it to remove duplicate grants and all but the first year of each funded project. This resulted in a set of 489 CBPR projects within the time and content criteria described above. Table 1 lists the number of funded projects by NIH research funding mechanism (e.g., R01, R24, P20, U54) associated with all 489 CBPR projects.

A preliminary review of grant applications and annual progress reports for the 489 projects found insufficient evidence of community partners and respective contact

Table 1 Number of NIH grants by grant mechanism, FY2004–2013

NIH grant mechanism	# of projects
P01	11
P20	40
P30	24
P50	8
P60	9
R01	77
R03	30
R21	89
R24	91
R34	9
RC1	7
RC2	4
RC4	10
U01	34
U54	46
Total	489

information. Consequently, we compiled a list of principal investigators (PIs) and corresponding email addresses for these projects, and sent emails requesting completion of a short form gathering information on up to three community partners per research grant. In our solicitation to PIs, we defined *community partners* as,

Organizations and/or individuals that were (or are) involved in the research process as members or representatives of the community defined by your grant. These include (but are not limited to) organizations such as tribal governments, colleges and other organizations, state or local governments, education institutions (such as junior colleges, minority colleges, school systems or districts, or primary and secondary schools), health care delivery organizations, health professional organizations, churches or other faith-based organizations, public housing resident councils, or advocacy organizations. Please note that if your grant involved a Community Advisory Board, the Community Partners would include those organizations and individuals that were members of this Advisory Board and were most actively involved in the CBPR grant.

We received responses from 174 of 411 unique PIs (42%) who provided information on 357 community partners from 204 projects. We used these individuals as our sample of community partners. Our project was reviewed by the National Institutes of Health's Center for Scientific Review and the Office of Management and Budget's Office of Information and Regulatory Affairs, Control #0925-0474. Principal investigators and community partners received an email

message from OBSSR that explained the purpose of the project, requested participation, and included a link to the online (investigator- or community-partner) questionnaire.

Methods

Both principal investigators and community partners were provided the following informed consent statement once they opened their respective links to the online questionnaire:

Informed Consent Form

OMB Control Number: 0925-0474 Expiration Date: February 2018

Identification of project: Office of Behavioral and Social Sciences Research (OBSSR) CBPR Principal Investigators (PI) and Community Partners (CP) Customer Satisfaction Survey.

Statement of age of subject: I am at least 18 years of age and wish to participate in a survey being conducted by the National Institutes of Health (NIH), Office of Behavioral and Social Sciences Research (OBSSR), Bethesda, MD 20892.

Purpose: The purpose of this survey is to examine the nature, structure, and accomplishments of CBPR research grants conducted during this ten-year interval. We greatly appreciate your willingness to help us with this study.

Procedures: Participants will be asked to access a web-based questionnaire and complete the questionnaire by a specific date. The total time involved, including instructions, will be no more than 20 min.

Confidentiality: All information collected in this survey will be kept secure to the extent permitted by law. I understand that the data I provide will be grouped with data that others provide for the purpose of reporting and presentation, and that my name will not be used.

Risks: I understand that the risks of my participation are expected to be minimal in nature.

Benefits, freedom to withdraw, and ability to ask questions: I understand that this survey is not designed to help me personally but that the investigators hope to determine satisfaction with the NIH Community-based Participatory Research Program and the ways the program can be improved. I am free to ask questions or withdraw from participation at any time and without penalty.

Contact information: For questions regarding the survey or any study-related issues, please contact [NIH employee email address]. If you have any technical questions and/or have difficulty accessing the survey, please contact [Contracted survey administrator email address and toll-free phone number].

Burden disclosure: Public reporting burden for this collection of information is estimated to average 20 min

per respondent, including the time required for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB Control Number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, Maryland, 20892-7974, ATTN: PRA# 0925-0668. Do not return the completed form to this address.

Agreement to Consent (Online Radial Buttons)

- I have read the information about this study, and I agree to participate.
- I have read the information about this study, and I do not wish to participate.

The questionnaires for both investigators and community partners purposefully included many parallel items. The PI questionnaire was designed to collect information on the nature of the CBPR project, its community participants, and the outcomes of the NIH-funded research project. Each instrument contained original measures and several adapted from external sources including the Research for Improved Health's Community-Engaged Research Instrument [13–15], the Partnership Self-Assessment Tool (PSAT) [16, 17], the Program Sustainability Assessment Tool [18], and a measure of community engagement in research [19, 20]. In addition, we asked whether a project added community members over time and whether the academic-community partnership continued beyond the NIH-funded period.

The Partnership Self-Assessment Tool asks respondents to rate partnership functioning using a 5-point scale in which 1 = not at all well, and 5 = extremely well [21]. Expressly tailored for CBPR, the tool can assess partnership synergy as (1) equal engagement of community partners in all aspects of research, (2) inclusion of diverse community perspectives, and, (3) long-term relationships between partners. See also [12]. In addition, we adapted measures to assess community partners' and PIs' engagement in 12 activities (1) writing grant applications, (2) conducting background research, (3) choosing research methods, (4) developing sampling procedures, (5) recruiting study participants, (6) implementing the interventions, (7) designing interview and/or survey questions, (8) collecting primary data, (9) analyzing collected data, (10) interpreting study findings, (11) writing reports and journal articles, and (12) giving presentations at meetings and conferences. See [19, 20]. We collected data from participants between October 15, 2015 and January 16, 2016.

Table 2 PIs' history of collaboration with community partners (n = 128)

	#	%
No partners had worked together previously	16	12
Fewer than half had worked together	61	48
Half or more had worked together	51	40
Total	128	100

Table 3 Community partners' history of collaboration with PIs (n = 95)

	#	%
No partners had worked together previously	31	32
Partners had worked with other researchers at same academic institution	14	15
Had collaborated with same PI previously	50	53
Total	95	100

Results

We received 133 usable responses from PIs/academic partners and 97 useable responses from community partners for a total of 230 responses. Response rates were similar; 133/381 or 35% of PIs, and 97/322 or 30% of community partners. We report on all respondent data and also on a specific subset of 37 projects for which an academic and community partner responded regarding the same project.

Prior History of Collaboration Between PIs and Community Partners

Tables 2 and 3 demonstrate many researchers and community organization members had pre-existing working relationships. For example, 88% of academic partners reported working with some or all the community partners on the NIH-funded project about which OBSSR asked them to report; 68% of community-based respondents reported working with the same researcher or other researchers at the same academic institution (see Table 2). That said, 32% of community partners had no previous relationship with researchers (see Table 3); 12% of academics responded similarly (see Table 2). NIH-funded projects built upon previous relationships and fostered new collaborations.

Perceived Funding Sufficiency

CBPR PIs and community partners were asked to rate the sufficiency of three financial and capital resources (funding,

Table 4 Perceived funding sufficiency, CBPR principal investigators (PIs) and community partners (CPs)

In terms of funding, this project had	CBPR PIs N (%)	CBPR CPs N (%)
None of what it needed	0	0
Little of what it needed	5 (4%)	4 (5)
Some of what it needed	25 (21.5)	18 (20)
Most of what it needed	62 (53)	47 (55)
All of what it needed	25 (21.5)	17 (20)
Total	117 (100)	86 (100)

Table 5 Community partners' history of collaboration among one another (n = 77)

	#	%
No prior collaboration with other CBOs	8	10
Previous collaboration with some CBOs	44	57
Prior collaborations with all other CBOs	25	33
Total	77	100

space, and equipment) using a five-point rating scale (1 = None of what the project needed, to 5 = All of what it needed). About three-quarters of the PIs and community partners concurred that their project had most or all the funding it needed (see Table 4). In fact, the perceptions of community partners and PIs on this topic reflected one another closely in all categories. For example, no participant agreed that projects had “none” of resources needed and approximately 5% of partners and PIs stated projects had “little” of needed resources, while 20% concurred that projects had all the resources needed.

Prior History of Collaboration Among Community Organizations

Table 5 demonstrates supportive and enduring relationships among community organizations and their members. That most respondents reported collaborating with some or all partner organizations on the NIH-grant-funded project about which each reported suggests a tightly knit infrastructure that nonetheless welcomes new members. The same can be said for all members in this partnership given that 88% of PIs reporting working with partners, 68% of community partners reporting working with academicians, and 90% of community organizations reported collaborating with one another.

PI Perspective on Community Engagement by Activity

Among the activities that academic partners reported that community partners were more involved than researchers

were recruitment and retention of project participants (41%), implementing the project's intervention (31%), and ensuring that project findings are put into community practice (34%). Investigators reported that community partners were equally involved in identifying the research problem to address (59%), developing the project's intervention (59%), and planning how to disseminate project results (59%).

Community Partner Perspective on Community Engagement by Activity

Community partners reported that they were more involved than academicians in the recruitment and retention of project participants (44%), implementing the intervention (31%), and maintaining the partnership once NIH funding ends (31%). The three activities with the largest proportions of community partners reporting an equal level of involvement with researchers were planning how and to whom to disseminate project results (71%), developing the project intervention (62%), and implementing the intervention (59%).

Academic and community partners tended to agree on their experiences, though differences of 10% or greater on participation included questionnaire development, scientific conference presentations, and writing scientific manuscripts. Community partners perceived themselves to have less involvement in writing scientific presentations and manuscripts than did academic partnerships.

Community Engagement in Research Assessment (CERA) Index and Community Partner Satisfaction

The analyses presented so far indicate that CBPR PIs and Community Partners agree that the latter are substantively involved in most of the activities comprising a research project. As seen in Table 6, the mean CERA Index scores reported by the CBPR PIs and Community Partners are quite similar. It is generally assumed within the CBPR literature that Community Partners are satisfied with higher levels of engagement in these activities. One way to examine that assumption is by asking the Community Partners to rate their satisfaction with their degree of participation for these activities. For that reason, a Satisfaction with Level of Community Engagement in Research Activities measure was constructed. Community Partners rated their satisfaction using a five-point scale, as seen in Table 7. Table 8 shows the correlation between each Partner's level of engagement and satisfaction with that level for each of the 19 CERA items.

Community Partner Satisfaction with Community Engagement Level

As stated earlier, of the survey responses we received, there were a total of 37 projects with a CPBR PI response and one or more community partner responses. A total of 49 community partners from the 37 projects responded. This

Table 6 Community Engagement in Research Activities (CERA) [19, 20] index, CBPR principal investigators' responses to, "What category best describes the community partners' role in each of the following activities?"

	No CP participation N (%)	CPs < PIs N (%)	CPs = PIs N (%)	CPs > PIs N (%)
Determining who the community partners would include	7 (6)	11 (9)	61 (50)	42 (35)
Identifying research problem to address	8 (7)	28 (23%)	71 (59%)	14 (12)
Choosing project's research methods	11 (9)	64 (53)	42 (35)	4 (3)
Developing project's intervention	5 (4)	27 (23)	69 (59)	16 (14)
Implementing intervention(s)	1 (1)	18 (15)	62 (53)	36 (31)
Deciding what information to collect from participants	7 (6)	45 (37)	62 (51)	7 (6)
Designing questionnaires and other data collection procedures	10 (8)	66 (54)	42 (35)	3 (3)
Recruitment and retention of project participants	4 (3)	21 (17)	47 (39)	49 (41)
Collecting project data	9 (7)	43 (36)	41 (34)	28 (23)
Analyzing project data	30 (25)	69 (57)	21 (17)	1 (1)
Interpreting findings from analyses	13 (11)	50 (41)	54 (45)	4 (3)
Planning project results dissemination efforts	6 (5)	27 (22)	71 (59)	17 (14)
Presenting project findings at scientific conferences	15 (12)	59 (49)	41 (34)	6 (5)
Writing scientific papers on project findings	18 (15)	79 (65)	19 (17)	5 (4)
Informing community about project findings	5 (4)	24 (20)	58 (48)	34 (28)
Informing relevant policy makers on project findings	10 (8)	26 (22)	54 (45)	30 (25)
Ensuring project findings are put into community practice	5 (4)	15 (13)	49 (49)	41 (34)
Developing new sources of funding to continue work begun by project	19 (16)	46 (38)	42 (35)	13 (11)
Maintaining continuation of partnership after NIH funding ends	12 (10)	31 (26)	68 (57)	9 (7)

Table 7 CERA [19, 20] index, CBPR community partners' responses to, "What category best describes the community partners' role in each of the following activities?"

	No CP participation N (%)	CPs < PIs N (%)	CPs = PIs N (%)	CPs > PIs N (%)
Identifying research problem to address	10 (11)	21 (24)	48 (55)	9 (10)
Choosing project's research methods	13 (15)	35 (40)	37 (42)	3 (3)
Developing project's intervention	3 (3%)	23 (26)	54 (62)	7 (8)
Implementing intervention(s)	2 (2%)	7 (8)	51 (59)	27 (31)
Deciding what information to collect from participants	9 (10)	24 (27)	48 (55)	7 (8)
Designing questionnaires and other data collection procedures	12 (14)	30 (34)	45 (51)	1 (1)
Recruitment and retention of project participants	4 (5)	10 (11)	35 (40)	39 (44)
Collecting project data	8 (9)	23 (26)	38 (43)	19 (22)
Analyzing project data	23 (26)	41 (47)	23 (26)	1 (1)
Interpreting findings from analyses	22 (25)	33 (33)	32 (37)	–
Planning project results dissemination efforts	11 (13)	10 (11)	62 (71)	5 (6)
Presenting project findings at scientific conferences	23 (26)	21 (24)	43 (49)	1 (1)
Writing scientific papers on project findings	27 (31)	33 (38)	27 (31)	1 (1)
Informing community about project findings	8 (9)	9 (10)	50 (57)	22 (24)
Informing relevant policy makers on project findings	17 (20)	18 (21)	42 (48)	10 (12)
Ensuring project findings are put into community practice	6 (7)	15 (17)	42 (48)	25 (28)
Developing new sources of funding to continue work begun by project	13 (15)	34 (39)	35 (40)	6 (7)
Maintaining continuation of partnership once NIH funding ends	11 (13)	11 (13)	39 (44)	27 (31)

Table 8 Correlation between community partners' CERA scores and satisfaction with CERA

Community engagement with research activities	Mean CERA item score	Mean satisfaction with CERA item score	Correlation of CERA index item and satisfaction with level of engagement
Determining who the community partners would include	3.03	4.28	0.41**
Identifying the research problem to be addressed	2.64	4.18	0.51**
Choosing the research methods for the project	2.34	4.07	0.43**
Developing the intervention(s) that would be used in the project	2.75	4.07	0.39**
Implementing the intervention(s)	3.18	4.1	0.42**
Deciding what information would be collected from project participants	2.6	4.01	0.47**
Designing interviews, surveys and other data collection procedures	2.4	4.02	0.41**
Recruitment and retention of project participants	3.24	4.22	0.50**
Collecting project data	2.77	4.13	0.42**
Analyzing project data	2.02	4.09	0.38**
Interpreting the findings from the analyses	2.11	4.06	0.43**
Planning how the results from the project would be disseminated and to whom	2.69	4.08	0.49**
Presenting project findings at scientific meetings and conferences	2.25	3.99	0.36**
Writing scientific papers on the project findings	2.02	3.95	0.32**
Informing the community about the findings from the project	2.95	3.99	0.42**
Informing relevant policy makers about the findings from the project	2.52	3.83	0.39**
Ensuring that project findings are put into practice in the community	2.98	3.93	0.34**
Developing new sources of funding to continue the work begun by this project	2.39	3.58	0.26*
Maintaining the continuation of the changes produced by the project after the funding ended	2.93	3.6	0.28**

*Correlation is significant at the $p < .05$ level**Correlation is significant at the $p < .01$ level

provided an opportunity to compare PI and community partner responses regarding the same projects. For an appropriate comparison, it was necessary to limit the number of partner responses to a single respondent for any funded research project. For the 12 projects with multiple responses, we applied two criteria to select the single respondent to represent the project. First, was to choose the respondent who provided the most thorough set of responses; second, was to select the partners for each of these 12 projects on an alphabetical basis. This resulted in a final set of 37 PIs and 37 community partners, each paired from the same project. To compare the PI and community-partner reports, we conducted a paired t-test on several of the measures discussed above. The results support a level of agreement between researchers and community partners. Table 9 demonstrates no significant difference in scores between community and PI partners on the same project.

Discussion

Our project found that NIH funded a robust range of community-based participatory research projects over the decade we analyzed. The 489 projects during this period ranged from collaboration-building projects (R24), exploratory/pilot projects (R21), though research (R01) and program (P-series) project grants. Many of the principal investigators and community partners who responded to our queries reported existing collaborations—between academicians and community organizations as well as among community organizations. Though many of our respondents reported pre-existing relationships, it is important to note that new

academic-community partnerships emerged during this period.

Our survey found that most community and academic partners believed their projects had sufficient funding to accomplish their work. Many responses suggest that academic and community partners recall their collaborations in similar ways. That said, results also suggest that there continue to be opportunities to enhance the balance of community- and academic-participation throughout the research design, study implementation, and dissemination processes.

Limitations

Though our results are heartening, they have limitations. The lack of information on community organizations and respective personnel in the NIH database led not only to extra work, but also to delays in contacting academic and community partners. Our results are limited by the availability and willingness of the respondents to complete our online questionnaire as well as to their respective recollections—particularly on projects completed earlier in the decade we sampled. In addition, the limitations of self-reported data apply to the questionnaire responses underlying analyses reported here. Nonetheless, the number of voluntary responses to our queries and the overall agreement on their community-based participatory experiences lead us to the following considerations.

Future Directions

The number, breadth, and complexity of the CBPR projects NIH funded during this period suggest that it is a

Table 9 Paired samples: T-tests for agreement of CBPR PIs and community partners

Scale	Paired differences	Paired differences	Paired differences	Paired differences	Paired differences	t-statistic	Degrees of freedom	Significance
	Means	Standard deviation	Standard error of mean	95% confidence interval of difference	95% confidence interval of difference			
				Lower	Upper			
Partnership synergy	−0.08244	0.71028	0.12757	−0.34297	0.1781	−0.646	30	0.523
Sufficiency of financial resources	0.08642	0.8603	0.16556	−0.2539	0.42674	0.522	26	0.606
Sufficiency of non-financial resources	−0.07813	0.7398	0.15101	−0.39051	0.23426	−0.517	23	0.61
Community engagement in research activities	0.15426	0.49472	0.09187	−0.03391	0.34244	1.679	28	0.104

well-established approach that facilitates research and advances practice. The number of NIH study sections, federally-chartered expert panels that review grant applications, has increased as well, including Clinical Management of Patients in Community-based Settings [22], Community Influences on Health Behavior [23], Community-Level Health Promotion [24], Dissemination and Implementation Research in Health [25], and Health Disparities and Equity Promotion [26]. Such panels demonstrate NIH's anticipation and ability to review scientific projects that rely on CBPR; and recognize it as a mature field that will continue to develop scientific knowledge, new researchers, and new community partners.

The research community and the NIH should work together to determine how to better capture and report lead community partner information. Equally, if not more important, public access to this information can provide a service to facilitate collaborations among researchers and community partners, so representatives of community-based organizations and research institutions can locate one another more easily and begin to collaborate.

The responses we received suggest a thriving field; that said, the discrepancies among community partners' and academics' recollections of research involvement—specifically questionnaire design, scientific conference presentations, and writing scientific manuscripts—suggest opportunities to train community organizations in research terminology and general research design and practices. Given the scope of our project, it would be conjecture to propose a specific curriculum or the means to deliver it (e.g., in-person workshops, online video, massive open online courses/MOOCs). Nevertheless, the responses to this study demonstrate that community members want to learn more about and to participate in research design and evaluation.

Increased knowledge in this area only can result in stronger partners, especially community partners who participate in recruitment, data collection, intervention, and other research-related activities. Increased knowledge of research practices also may help community organizations to adapt questionnaires and analytic practices for projects once NIH funding ends—so the organizations can ensure quality, evolve and develop programming, and pursue other funding or reimbursement for services. Moreover, future academic collaborations with more scientifically-informed community partners may move more swiftly toward applications for research funding, as our findings suggest that CBOs do very well at identifying the health problems they want academics to help them resolve.

Academic health researchers may look to enhance their community partners' interests not only to promote good partnerships and healthier people, but also to foster stronger community organizations, research project employees, and future generations of scientists. It is beyond the scope of

our project to posit the previous statement as a finding from our data. We believe, however, that healthier communities, vibrant organizations that foster health and wellbeing, and the lives enriched through such environments may be the best possible result of community-based participatory research, and that our project demonstrates that NIH-funded research projects contribute to fulfilling that goal.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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