

Request for Information: Stakeholder Input on Opportunities for Increased Collaboration to Advance Prevention Research

Analysis of Public Comments

Received by the NIH Office of Disease Prevention

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Introduction

On February 13, 2020, the Office of Disease Prevention (ODP) published a [Request for Information \(RFI\)](#) to identify opportunities to foster and engage in partnerships and dialogue with stakeholders to advance prevention research.

The RFI was open for a total of 45 days and comments were accepted through an online form. The ODP encouraged input from researchers in academia and industry, health care professionals, patient advocates and advocacy organizations, scientific or professional organizations, federal agencies, and other interested members of the public. We asked these groups to provide input on the following areas:

- Strategies for increasing collaboration and engagement
- Suggestions for how to foster high-quality collaborative prevention research and in what areas
- Resources that would be helpful to organizations to advance prevention research
- Scientific meetings that might benefit from ODP participation.

Responses

The ODP received 74 responses to the RFI. Comments were submitted by individuals, federal government employees, patient advocates, health care professionals, researchers in both academia and industry, and professional societies. About 19% of the comments were submitted on behalf of organizations and their members. Many respondents offered more than one recommendation within a topic area. Though most stakeholders provided comments in several topic areas, not all respondents answered every question. Key points raised in the comments are summarized below by topic area.

We thank all respondents for their thoughtful comments in response to this RFI. The ODP welcomes continued dialogue with our stakeholders to discuss the topics identified in this report and to further enhance collaboration and engagement. We can be reached at prevention@nih.gov.

Topic Area 1: The top two to three strategies for increasing collaboration and engagement between the ODP and your organization.

The most common response for how to increase collaboration and engagement was to expand research and/or funding of prevention science (n=27), especially for community-based partnerships (n=9), health equity/health disparities (n=8), and dissemination and implementation research (n=7). Several disease areas were mentioned, but lifestyle behaviors that can manage and prevent chronic disease were cited most often (n=7), including diet/nutrition (n=3), sleep (n=2), tobacco (n=2), and exercise (n=1).

There was a desire by some stakeholders for the ODP to take the lead in identifying evidence-based interventions (n=4) and research methods (n=4) that could be implemented in communities and health care organizations across the nation. Respondents also wanted increased support for clinical trials and randomized controlled trials (n=4). Funding for transdisciplinary research (n=4) was also mentioned as an area that deserved increased attention; this included suggestions like increased funding for multisector collaborations to reach underserved populations and funding opportunities that require prevention practitioners and research entities to form consortiums.

One stakeholder also recommended the ODP create career development programs to increase opportunities for research careers in family medicine. The programs could include training “new investigators to develop prevention-related research skills, especially within communities and among undifferentiated patient populations.”

The second most commonly cited strategy for increasing collaboration and engagement was for the ODP to facilitate knowledge sharing and build relationships with stakeholders (n=21). Many stakeholders suggested that the ODP create opportunities for experts to convene and share their knowledge and advance prevention research priorities either through targeted task forces or through internal meetings with the Office (n=7). This included suggestions such as creating designated positions for experts to serve on ODP advisory committees and organizing meetings that bring together partners from across the health care spectrum to address disparities and improve health in specific disease areas. Increased participation by the ODP in conferences and scientific meetings was also mentioned by several stakeholders as an effective strategy for enhancing collaboration among different organizations (n=7).

Building relationships with the health care community was the third most mentioned strategy to increase collaboration and engagement (n=14). Since primary care is so integral to prevention, several stakeholders (n=4) mentioned the importance of including community health centers, patient advocates, physicians, and others in the health care community in the research process and working with them to implement evidence-based prevention strategies. Two respondents also mentioned wanting the ODP to improve opportunities to recruit and enroll patients in clinical trials.

Other strategies for increasing engagement and collaboration included increasing information dissemination (n=6), developing additional resources (n=5), and focusing on health literacy (n=3). In terms of resources, two stakeholders recommended the ODP develop an online registry for researchers. One stakeholder suggested the registry be a catalogue of preventive services. The other idea was for the registry to be a place for researchers who are working together to “store and share preventive initiatives, efficacy studies, methods, and other ongoing initiatives.” Other suggestions included developing online courses and webinars on research methods for young investigators (n=1), creating resources for students and trainees about the social determinants of health (n=1), and developing continuing education opportunities for nurse practitioners (n=1). When developing materials and resources, one stakeholder mentioned the importance of developing materials in multiple languages.

Topic Area 2: Suggestions for how the ODP can foster high-quality collaborative prevention research and in what areas.

Like Topic Area 1, the most common response to how the ODP can facilitate high-quality collaborative prevention research was to increase research and/or funding (n=22). The responses spanned several topic areas and recommended a focus on research that requires collaboration. Of those who made suggestions related to increasing research and/or funding, two stakeholders recommended the ODP encourage the National Institutes of Health (NIH) to increase the length of awards so principal investigators do not have to compete so often for funding.

The second and third most recommended strategies were to facilitate knowledge sharing and build relationships with stakeholders (n=17) and community outreach/engagement (n=10), including engaging with community members throughout the entire research process. Four stakeholders who responded to Topic Area 2 suggested that the ODP host conferences or workshops to bring together experts and research organizations (public, private, or otherwise), with the primary aim of providing training and mentoring in novel research methods and design (n=2) or promoting innovation and establishing a path forward in a particular disease or topic area (e.g., Type 2 diabetes, health disparities) (n=2).

Health care providers were the most frequently recommended collaborator for the ODP (n=10). This included suggestions like partnering with primary care providers to study disparities in preventive services implementation and cultivate more research on de-implementation of less effective prevention activities; fostering awareness of the importance of research to clinical practice; developing research projects that target established quality indicators in clinical care; and ensuring that a broader range of health care providers than just physicians (e.g., nurse practitioners) are represented in prevention research to better reflect the current health care workforce. Communities/community stakeholders (n=8) and federal agencies (n=5) were also mentioned as potential collaborators for the ODP. The Centers for Disease Control and Prevention (n=3) was specified in some of the recommendations to collaborate with other federal agencies, as was the Centers for

Medicare & Medicaid Services (n=3). Several stakeholders recommended working with non-traditional partners (n=5) like educational, housing, transportation, and economic organizations.

The most frequently mentioned health condition/disease that respondents cited as needing more prevention research was chronic disease (n=11). Stakeholders tended to name specific conditions when talking about chronic diseases, with diabetes being mentioned the most (n=4). Behavioral health (n=10) and cancer (n=8) were also high priority areas. Seven stakeholders recommended the ODP focus on interventions. Comorbidities were mentioned three times as an area that deserved more attention, as was tobacco/electronic nicotine delivery systems/smoking.

The prevention research area/activity identified by stakeholders as most in need of collaboration was education and training (n=16), both for researchers and health care professionals (n=11) as well as for the general public (n=5). As recommended by one stakeholder, the ODP should, "(a) extend these collaborative efforts in prevention research to NIH-sponsored training programs to develop competencies in the kind of team science required for prevention research to be most impactful, and (b) ensure these new collaborative opportunities are available for junior researchers so that the next generation of prevention scientists benefits from a robust prevention science portfolio." Primary prevention—defined by the ODP as either identifying risk factors for a health condition/disease or preventing the onset of a new condition—and prevention methods/measurements were each mentioned by stakeholders 12 times as areas where the ODP should focus.

Many respondents recommended the ODP focus on dissemination and implementation/evaluation research by collaborating with transdisciplinary researchers and community stakeholders (n=10). The economics of prevention (n=9) was also cited as an area in need of attention from the ODP and its stakeholders, often with the suggestion that the ODP should develop reports or models that identify the economic value of preventive strategies (n=4). One stakeholder recommended the ODP develop a "how-to guide" for the NIH grants process that includes "consensus-driven ingredients of what should be included in a successful prevention-focused NIH research grant."

Topic Area 3: The two to three resources (e.g., training courses, fact sheets, infographics, videos) that would be most useful for your organization.

Though most stakeholders were interested in more than one resource format, the type of resource most often identified as being the most useful was training courses (n=22), particularly free and online courses (n=5). The next most recommended resources were fact sheets (n=15), videos (n=14), and infographics (n=14). Many respondents did not specify the resource topics. Among those who did, dissemination and implementation resources (n=8), research methods (n=5), funding (n=5), and nutrition (n=5) rose to the top.

Respondents primarily highlighted the need for resources for researchers (n=28) and health care professionals (n=21). However, there was also a significant amount of interest in resources for the general public (n=18). A small number of respondents offered suggestions of their own resources for ODP to share.

Topic Area 4: The scientific meetings that might benefit from ODP participation.

The most mentioned scientific meeting that might benefit from participation by the ODP was the American College of Preventive Medicine Annual Conference (n=10) followed by the American Public Health Association Annual Meeting (n=7), the Society of Behavioral Medicine Annual Meeting (n=5), and the North American Primary Care Research Group Annual Meeting (n=5).

In addition to scientific meetings, several stakeholders recommended meeting with community organizations (n=4) such as local community centers, religious sites, schools, and libraries since, as one stakeholder mentioned, "academic meetings only reach the tip of the iceberg."

In Summary

There was a lot of enthusiasm among researchers, professional organizations, community members, and other stakeholders for more prevention research and/or funding especially in areas that impact chronic disease such as nutrition, sleep, and other lifestyle factors. Several stakeholders recommended taking a transdisciplinary approach to research and involving non-traditional partners from educational, housing, transportation, and economic organizations. There was also a push among stakeholders to include members from the community and/or professional organizations in the research process.

There was a great deal of interest among stakeholders for the ODP to help support dissemination and implementation efforts in the community. This included both identifying evidence-based strategies for disease prevention and creating resources that highlight these strategies. Stakeholders also recommended working with members of the health care community to implement and evaluate these approaches.

There was a desire among stakeholders for the ODP to organize meetings to identify prevention needs, share expertise, and/or create actionable recommendations. Stakeholders also recommended the ODP increase their participation in scientific meetings to enhance collaboration and foster high-quality collaborative prevention research.

Lastly, several stakeholders expressed a desire for more investment and resources in prevention methods and/or measurement. These recommendations sometimes took to the form of requests for the ODP to provide more training in research methods and measures or to develop new/better methods, while other respondents

made the more general statement that it is a critical component of prevention research that deserves continued attention.