

July 12, 2019

Cindy Caughman, M.P.H.
Chief, Scientific Planning, Policy, and Analysis Branch
National Institute of Arthritis and Musculoskeletal and Skin Diseases
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Bethesda, MD 20814

Re: Request for Information (RFI) on the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Strategic Plan for Fiscal Years (FY) 2020-2024 (NOT-AR-19-010)

via: niamslrpfeedback@mail.nih.gov

Dear Ms. Caughman:

On behalf of the 3,350 individual and 107 institutional members of the American Association for Dental Research (AADR), thank you for the opportunity to submit comments in response to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Strategic Plan for Fiscal Years (FY) 2020-2024. While the National Institute of Dental and Craniofacial Research (NIDCR) is the NIH IC that provides the greatest level of funding to dental institutions, NIAMS was the second largest NIH IC funder of research at U.S. dental institutions from 2005-2014. Therefore, AADR members have a vested interest in the research activities and priorities of NIAMS.

NIAMS is currently funding research projects that have broad implications for dental, oral and craniofacial health. These include but are not limited to temporomandibular joint disorders (TMJD); cleft palate and other disorders related to craniofacial development; autoimmune diseases such as Sjögren's syndrome; dental implants and new biomaterials; bone biology and diseases; physiology and pathology of oral connective tissue; salivary diagnostics; and periodontitis. AADR was pleased to see interaction between the skin, oral cavity and other microbiomes specifically mentioned as a potential research direction within skin biology and disease research in the strategic plan. NIAMS should maintain a robust dental, oral and craniofacial disease research portfolio through FYs 2020-2024.

AADR supports the cross-cutting themes described in the strategic plan, particularly the themes of precision medicine, patient-centric research and inclusion of diverse populations in biomedical research.

In November 2018, AADR hosted a symposium entitled, Advances in Precision Oral Health (http://www.iadr.org/2018ffs/agenda), where researchers gathered to discuss the promise that precision medicine

¹ Ferland CL, O'Hayre M, Knosp WM, Fox CH, Horsford DJ. 2017. The NIH's funding to US dental institutions from 2005 to 2014. Journal of Dental Research. 96(1): 10–16.

holds for improving prevention, diagnosis and treatment of dental, oral and craniofacial diseases. The symposium included presentations on pain, the oral microbiome, dental caries and oral cancer, among others. As a follow up, AADR and the J. Craig Venter Institute will host another symposium in November 2019 entitled, *Integrating Omic Datasets Towards Translation* (http://www.iadr.org/2019ffs/agenda), which will focus on methods for understanding the oral microbiome and its role in health and disease. Developments in precision medicine for arthritis and musculoskeletal and skin diseases could have implications for dental, oral and craniofacial diseases and vice versa as one disease can affect multiple organ systems.

AADR is committed to elevating patients' voices in research. AADR operates the programmatic activities of the Friends of National Institute of Dental and Craniofacial Research (FNIDCR),² a broad-based coalition of academic and research institutions, professional associations and foundations that champion NIDCR and represents the interests of FNIDCR. Members of the FNIDCR Patient Advocacy Council³ represent patients with diseases that affect the dental, oral or craniofacial complex such as ectodermal dysplasia, lupus, scleroderma, Sjögrens, osteogenesis imperfecta and others. Therefore, AADR supports the NIAMS strategy of "including patients as partners in the development of research questions, directions, and priorities...in efforts to improve the development and testing of new therapies".

Patients provide an important perspective on life with disease, especially chronic, currently incurable diseases; treatment side effects that may influence compliance and quality of life; and patient priorities to help direct research efforts. One recent example is the powerful first-hand accounts given by individuals with TMJD at a National Academy of Medicine workshop. Patients described frustrating experiences with receiving a proper diagnosis; pain associated with TMJD and the often debilitating effects of unsuccessful treatment efforts.⁴

Specifically, regarding the effort to study the patient experience by "promoting development and testing of measures, wearable devices, and biosensors to assess physical function and other outcomes," NIAMS should collaborate with NIDCR, which as of the submission of this response, is evaluating research proposals to accelerate the development of intraoral biodevices to monitor patients in health and disease.⁵

Another area where NIAMS and NIDCR may wish to collaborate is on the common goal of "advancing dissemination and implementation research and methods to encourage the application of research advances in

² Friends of the National Institute of Dental and Craniofacial Research. Alexandria, VA: American Association for Dental Research; [accessed 10 July 2019]. http://www.iadr.org/AADR/Government-Affairs/Friends-NIDCR.

³ Friends of NIDCR Patient Advocacy Council. Alexandria, VA: American Association for Dental Research; [accessed 10 July 2019]. http://www.iadr.org/AADR/Government-Affairs/FNIDCR-Patient-Advocacy-Council.

⁴ Temporomandibular Disorders (TMD): From Research Discoveries to Clinical Treatment: A Workshop. 28-29 March 2019. Washington, D.C.: Health and Medicine Division, National Academies of Sciences, Engineering and Math. http://www.nationalacademies.org/hmd/Activities/PublicHealth/TemporomandibularDisorders/2019-MAR-28.aspx.

⁵ Enabling Technologies to Accelerate Development of Oral Biodevices (R21 Clinical Trial Not Allowed). Bethesda, MD: National Institute of Dental and Craniofacial Research, National Institutes of Health, U.S. Department of Health and Human Services; [accessed 10 July 2019]. https://grants.nih.gov/grants/guide/rfa-files/rfa-de-19-008.html.

health care settings," especially for arthritis and musculoskeletal and skin diseases that affect the oral cavity. NIDCR and other institutes and centers have participated in NIH-wide Dissemination and Implementation Funding Opportunity Announcements for several years. 6 NIAMS should consider participating in this effort.

AADR also supports the cross-cutting theme of including diverse populations in biomedical research. Too often clinical trials do not include people from diverse backgrounds, meaning that those from underrepresented groups do not benefit from treatments tested in trials and that results of trials do not necessarily apply to people with diverse genetic backgrounds. Medicine cannot be called precise when clinical and genetic results are derived from mostly white participants. NIAMS should encourage active recruitment of groups historically underrepresented in clinical trials and wherever possible, address barriers that discourage participation of these groups, including past negative experiences of communities of color with medical research.^{7, 8}

Finally, AADR is pleased to see workforce diversity included in the strategic plan and encourages NIAMS to actively engage with professional societies on this measure. AADR has made substantial efforts to increase the representation and inclusion of women and underrepresented racial/ethnic groups within the Association and in the broader dental, oral and craniofacial research community. Many of these activities are mediated through the Women in Science Network (WISN), which is a function of AADR's parent organization, International Association for Dental Research (IADR), and the AADR Committee on Diversity and Inclusion (CDI). WISN promotes the interests of women, communication, research collaboration and career mentoring among female members. WISN examines and highlights issues related to women professionals such as evidence on policies and benefits such as childcare, tenure clock with child birth/adoption, recruitment, salary, etc. and leadership skill building for women. The CDI evolved from an earlier task force and is charged with developing programs for promoting diversity and inclusion within AADR and the dental, oral and craniofacial workforce. Other professional societies have similar groups, and scientific meetings provide a great forum for discussing and strategizing on workforce diversity issues.

AADR and other professional societies have also been active in combatting sexual harassment in science. AADR is a founding member of the Societies Consortium on Sexual Harassment in STEMM. While the strategic plan addresses underrepresented racial and ethnic groups in the workforce, there is no mention of how NIAMS engages in NIH-wide efforts on preventing and reducing harassment in science, which can cause women to leave the scientific workforce. As NIH continues to develop polices and procedures for addressing harassment in both the intramural and extramural research communities, AADR encourages NIAMS to actively communicate these new measures to its stakeholders.

⁶ Implementation Science and Oral Health. 2018. Bethesda, MD: National Institute of Dental and Craniofacial Research, National Institutes of Health, U.S. Department of Health and Human Services; [accessed 10 July 2019]. https://www.nidcr.nih.gov/grants-funding-priorities/implementation-science-and-oral-health.

⁷ Knepper TC, McLeod HL. 2018. When will clinical trials finally reflect diversity? Nature. 557:157-159.

⁸ Popejoy AB, Fullerton SM. 2016. Genomics is failing on diversity. Nature. 538: 161–164.

⁹ National Academies of Sciences, Engineering, and Medicine. 2018. Sexual Harassment of Women: Climate, Culture, and Consequences in Academic Sciences, Engineering, and Medicine. Washington, DC: The National Academies Press.

Once again, AADR is grateful for the opportunity to provide comments on the NIAMS Strategic Plan for Fiscal Years (FY) 2020-2024. AADR stands ready to assist NIAMS as this plan is finalized. Please do not hesitate to reach out to Dr. Seun Ajiboye, Director of Science Policy and Government Affairs, at sajiboye@iadr.org if you need any additional information.

Sincerely,

Christopher H. Fox, DMD, DMSc

Chief Executive Officer

J. Timothy Wright, MS, DDS

President