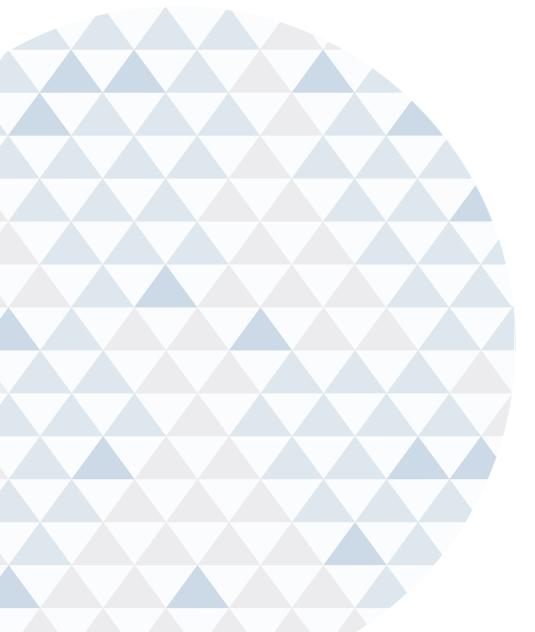
ADVOCACY TOOLKIT AL



Furthering funding and policies for the advancement of dental, oral and craniofacial research worldwide.





Dear Advocates:

At the International Association for Dental Research (IADR), we are guided by a three-part mission to advance research and increase knowledge for the improvement of oral health worldwide; support and represent the oral health research community; and facilitate the communication and application of research findings. As we work to carry out our mission and support our members across the world, there is an equally important role for the dental, oral and craniofacial research community to play in developing new research programs; positioning our field as a leader, innovator, and critical link in the biomedical research enterprise; and addressing regulatory changes that are needed to improve oral and overall health.

Future advances in health care depend on a sustained global investment in basic research to identify fundamental causes and mechanisms of disease, accelerate technological development and discovery, and ensure a robust pipeline of creative and skillful biomedical, clinical, public health, and translational researchers. To help ensure these advances are sustained, IADR is working to support our members to create and execute advocacy campaigns to advance promising dental, oral and craniofacial research; increase oral health research funding opportunities; and utilize research findings to inform health policy development.

This Advocacy Toolkit is designed to provide our members across the world with resources to develop advocacy campaigns to increase governmental funding for dental, oral and craniofacial research. It is our hope that by conducting effective advocacy campaigns, our members can secure additional governmental resources for grants, research, and other public health and health research programs. Advocacy is an important mechanism through which we can raise our collective voices and ultimately make a difference for the populations we serve through our research.



Our intention is for this toolkit to be a living document; we plan to continuously update it to suit the needs of our members in different parts of the world. We believe this toolkit is an important step in our enduring efforts to raise the visibility of our field throughout the world.

We look forward to your partnership in this journey.

Sincerely,

Cantagle It 702

CHRISTOPHER H. FOX, DMD, DMSc, CHIEF EXECUTIVE OFFICER International Association for Dental Research

TA BORENTS OF

. 2
. 3
. 3
. 4
. 8
12
26
29
45
53

LIST OF COMMON ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
DMFT	Decayed, missing or filled teeth
FDI	FDI World Dental Federation (Fédération Dentaire Internationale)
HIV	Human immunodeficiency virus
IADR	International Association for Dental Research
NCD	Non-communicable disease
R&D	Research and development
SMART	Specific, measurable, achievable, relevant, time-bound
UN	United Nations
USD	United States Dollar
WHO	World Health Organization

ORAL HEALTH IS A GLOBAL ISSUE

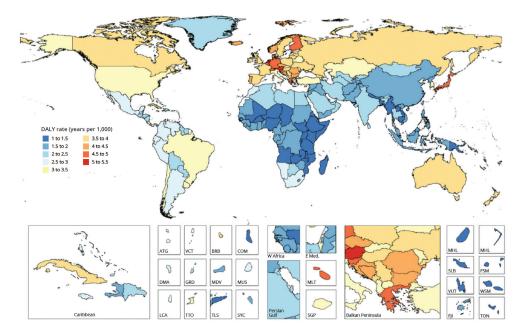


Oral health is essential to overall health. It affects our "ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions."¹ Sharing common risk factors with other chronic diseases and systemic conditions, oral health has also been linked to diabetes, cardiovascular disease, HIV/AIDS, Alzheimer's disease, and other diseases. In addition, the oral cavity can reflect manifestations of many diseases and saliva can contain biomarkers of cancers and other diseases.

Unfortunately, oral diseases—from dental caries to periodontal disease to oral cancers—remain prevalent and result in pain and disability for individuals across the globe. They also present a tremendous economic burden around the world.

¹ FDI's definition of oral health:

https://www.fdiworlddental.org/oral-health/fdi-definition-of-oral-health



World map of age-standardized disability-adjusted life year (DALY) rates²

(per 1,000 population) for all oral conditions combined in 2015, both sexes.

 DALY rate (years per 1,000)

 1 to 1.5
 3.5 to 4

 1.5 to 2
 4 to 4.5

 2 to 2.5
 4.5 to 5

 2.5 to 3
 5 to 5.5

3 to 3.5

According to the World Health Organization (WHO), several oral conditions are considered public health issues worldwide³:

Dental Caries

Dental caries is one of the most prevalent diseases globally, affecting between 60-90 percent of school-aged children and almost 100 percent of adults worldwide.

Oral Cancer

Oral cancer is the eighth most common cancer worldwide, where the average oral cancer rates in most countries range from one to 10 cases per 100,000 people. Men, older people, and people of low education and income are some of the populations with higher oral cancer prevalence.

Periodontal Disease and Tooth Loss

Periodontal diseases result from an inflammation and infection of the gums. Its more serious form, periodontitis, if left untreated, leads to an increased risk of tooth loss. Severe periodontal disease was the 11th most prevalent disease globally in 2016,⁴ and severe tooth loss and edentulism, meaning there are no natural teeth remaining, are widespread, particularly among older people.

³ Oral Health Information Sheet

http://www.who.int/news-room/fact-sheets/detail/oral-health

² N.J. Kassebaum, A.G.C. Smith, E. Bernabé, T.D. Fleming, A.E. Reynolds, T. Vos, C.J.L. Murray, W. Marcenes (2017). Global, Regional, and National Prevalence, Incidence, and Disability-Adjusted Life Years for Oral Conditions for 195 Countries, 1990–2015: A Systematic Analysis for the Global Burden of Diseases, Injuries, and Risk Factors. J Dent Res, 96(4), 380–387.

⁴ GBD 2016 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet.* 2017;390(10100):1211-1259.

HIV-related Oral Infections

About half of all HIV-positive people suffer from an oral fungal, bacterial, or viral infection. Having certain rare oral infections are often considered among the earliest symptoms of HIV.

Oro-dental Trauma

Due to a range of issues, including unsafe schools and playgrounds, accidents and violence, between 16-40 percent of children aged six to 12 years old are affected by dental trauma.⁵

Cleft Lip and Palate

Cleft lip and palate are among the most common craniofacial birth defects. While these defects occur in roughly one per 500-700 births, the rate varies significantly across different geographical areas and ethnic groups.

Noma (Necrotizing Ulcerative Stomatitis)

Noma is a disfiguring oral infection that affects children living in extreme poverty primarily in Africa and Asia. The disease spreads quickly, and if left untreated, is fatal in almost 90 percent of those affected.

According to the Global Burden of Disease 2015 study⁶, nearly half of the world population suffered disability from oral conditions in 2015, and the report revealed the tremendous unmet demand for dental care. As of 2015:

276 million people were affected by tooth loss

538 million people suffered severe periodontal disease

573 million children had untreated caries in deciduous teeth

2.5 billion people had untreated caries in permanent teeth

3.5 billion people had untreated oral conditions

⁵ World Health Organization, "What is the burden of oral disease?" https://www.who.int/oral health/disease burden/global/en/

⁶ N.J. Kassebaum, A.G.C. Smith, E. Bernabé, T.D. Fleming, A.E. Reynolds, T. Vos, C.J.L. Murray, W. Marcenes, and GBD 2015 Oral Health Collaborators. (2017). Global, Regional, and National Prevalence, Incidence, and Diability-Adjusted Life Years for Oral Conditions for 195 Countries, 1990-2015: A Systemic Analysis for the Global Burden of Diseases, Injuries, and Risk Factors. Journal of Dental Research, 96: 380-387.

In addition to the oral conditions outlined by the WHO, dental, oral and craniofacial conditions also encompass a range of diseases that impede quality of life, are physically debilitating, and create significant financial and social burden to those affected. These include complex systemic diseases that have a major oral health component, including temporomandibular joint (TMJ) disorders; autoimmune disorders, such as Behcet's disease and Sjögren's Syndrome; and genetic developmental diseases, such as Cleidocranial Dysplasia, Ectodermal Dysplasia and Fibrous Dysplasia.

Equally staggering to the physical impact of oral conditions is the economic impact oral conditions have on individuals and society overall. A 2015 study in the *Journal of Dental Research* estimates that the global economic impact of dental disease in 2010 amounted to \$442 billion USD. Within that amount, direct dental disease treatments costs were estimated to be roughly \$298 billion a year, and the indirect costs, primarily attributed to productivity losses, amounted to \$144.25 billion a year.⁷



Treatment without prevention is simply unsustainable."

- BILL GATES, XVI International AIDS Conference Keynote Speech

These numbers show that despite the progress that has been made on the prevention and treatment of oral diseases and conditions, they remain a widespread and costly part of society – not only in terms of treatment, but also in terms of productivity loss in the labor market. Fortunately, many oral diseases can be treated or prevented relatively easily, presenting an opportunity for researchers and public health practitioners to relieve disease burden for much of the population. But it is up to oral health research stakeholders to make that connection for policy and decision makers, and they can do so through advocacy.

The information provided throughout this toolkit may be used broadly to provide context and to make the case to policymakers throughout the world about the need for increased investments in dental, oral and craniofacial research.

⁷ S. Slistl, J. Galloway, P.A. Mossey, W. Marcenes. (2015). Global Impact of Dental Diseases. J Dent Res. 94(10): 1355-61.

WHAT IS ADVOCACY AND WHY DOES IT MATTER?

This toolkit is designed to provide a living framework for members of IADR who wish to engage in advocacy to influence change, whether that's increasing funding for dental, oral and craniofacial research or informing policy decisions that can lead to improvements in oral health priority areas worldwide.

At the outset, IADR would like to remind our members that when developing any advocacy campaign, it is critically important to remember that one size does not fit all. Due to vast cultural, political and institutional differences across regions, everything from target audiences to campaign tactics and communications will need to be tailored to the user's respective country or region and adapted to fit within the context of that country or region's priorities. As individuals consider how best to approach a campaign—and if personal research does not provide the desired insight—individuals may also consider consulting with someone local who is adept at navigating the respective political system.



Defining Advocacy

In thinking about the design of an advocacy campaign, many people might worry about the implications of "lobbying" and ensuring the campaign is compliant with local laws. While it is certainly helpful to be aware of your local, state, or national government's rules in this regard, it is also important to keep in mind that in most democratic countries, as a citizen, you have the right to express your views and educate policymakers about the importance of oral health research and the role the government can play in its advancement. In almost all cases, you can play the role of an advocate for your own work without needing to worry about lobbying laws and registration. For those whom advocacy and lobbying are not an option, there may still be opportunity for you to educate and to work alongside policymakers by finding shared interests, such as political or economic interests, that move you toward a shared policy goal.

Education of policymakers about a specific disease or health care priority like dental, oral and craniofacial research is one simple form of advocacy that could help to inform the decision-making process. Remember that in most cases, policymakers are expert at just that: making and implementing public policy, but rarely are they experts in the subject matter of those polices—that is where you come in as an oral health expert. The key here is learning how to craft your message in a way that translates science into understandable and attainable policy. You can use the examples and guidance in this toolkit to help shape your message, create educational campaigns or programs, or even influence policymakers directly.

Another kind of advocacy is **grassroots mobilization** or **activism**. This type of advocacy usually involves a group of concerned citizens working together to make a statement about policies with which they might disagree. Perhaps one of the best-known examples of activism is the engagement of AIDS patients in the early days of the AIDS epidemic to push governments and pharmaceutical companies to invest in the research needed to develop antiretroviral drugs.



9

YOUR VOICE MATTERS



A small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

- MARGARET MEAD, Anthropologist

Direct lobbying is another form of advocacy that most often involves a lobbyist or other government relations or public policy professional working to specifically influence a piece of legislation, regulation, or funding measure. In most cases, "lobbying" is a professional activity, and "advocacy" is a citizen's activity—a distinction most clearly defined by the question, "Are you being paid for your advocacy work?" Chances are, the answer for those using this framework is "no," so put on your advocacy hats and let's get going!⁸

As you can see, the term "advocacy" is often attributed to a range of activities; as such, it may hold different meaning for different people.

For the purposes of this toolkit, IADR is defining advocacy as a process by which an individual or group aims to influence decisions within political, economic, or social systems and institutions. In other words, advocacy occurs when people champion an issue or cause with the ultimate goal of changing policy or practice.

⁸ If you are interested in learning more about lobbying regulations, check out "Regulation of Lobbyists in Developed Countries: Current Rules and Practices," (https://www.housing. gov.ie/sites/default/files/migrated-files/en/Publications/LocalGovernment/Administration/ FileDownLoad%2C2048%2Cen.pdf). In many developing countries, formal lobbying regulations have yet to be established although this is slowly changing. To learn more about the comparison between lobbying and corruption or bribery activities in low-income countries, check out the article published by Public Choice, "Lobbying, corruption and political influence," by Nauro F. Campos and Francesco Giovannoni in 2006, available at https://link.springer.com/article/10.1007/s11127-006-9102-4.



So, Why Advocate?

Advocacy can lead to increased awareness about an issue or cause, not only among policymakers, but also among other organizations and members of the general public.

In a time of limited funding, it is often incumbent on stakeholders to make their case in order to secure the tools and resources they need to be able to conduct their work. For dental, oral and craniofacial researchers, it is up to the research community and dental practitioners to show that oral health is intrinsically linked to overall health, and advocacy campaigns can provide the needed education about oral health issues, such as the incidence and economic burden of oral diseases. These initiatives may also lead to valuable partnerships with the broader oral health, medical and patient communities, which may, in turn, help leverage additional public and private financial support for research.

STAY LOUD TO STAY RELEVANT

66

The research community needs to stay loud...Your opinions are important—you need to make yourselves heard...The competition for this money will just become tougher and tougher until the final decisions are made."

- EDIT HERCZOG, Member of European Parliament from Hungary, on Horizon 2020

Ultimately, a better question for our purposes might be, "Why not advocate?" Any effort to shed light on the benefits of and build support for dental, oral and craniofacial research among stakeholders is positive and is more likely to lead to increased patronage for this work.

BUILDING AN ADVOCACY STRATEGY



Successful advocacy is the result of research, strategic planning and thoughtful execution. Developing an advocacy strategy is foundational to being effective because it creates a roadmap for appropriate use of resources and time while also minimizing risk and maximizing opportunity. An advocacy strategy should incorporate the country's political structure, context, and key decision makers; gather and present the information that will be most effective in making your case; and develop tools and resources that can help you achieve your goal. This chapter contains elements that individuals and organizations will want to consider when building out an advocacy strategy.

ESTABLISH THE ADVOCACY GOAL

Prior to launching any type of advocacy campaign, you must identify the specific problem or issue that you are trying to solve. For researchers, do you want to increase overall funding streams for dental, oral and craniofacial research? Or is your goal more research-oriented, such as raising the number of funding opportunity announcements within a specific area of research or ensuring that oral health research is included in a broader health research agenda?

Once the overarching issue has been identified, you must set clear goals and SMART (specific, measurable, achievable, relevant and time-bound) objectives that lay a strong foundation for success.

SMART GOALS

Specific – Provide sufficient detail about what needs to be done to achieve goals

Measurable – Ensure objectives are written so you can evaluate progress and success

Achievable – Make sure the goals are attainable (in terms of tools, resources, time, etc.)

Relevant – Confirm that the goals are consistent and fit with long-term plans

Time-bound – Set a target deadline by which to complete tasks

Advocacy goals should clearly state the desired change, outline who will make that change, and by how much and when. It is also important to note that advocacy is often a long game and not something that can often be achieved in days, weeks, or even months. It takes time and effort to build a foundation for advocacy, particularly since much of that foundation centers on building relationships with the people you are trying to influence.

2. IDENTIFY TARGET AUDIENCES

Once an advocacy goal has been established, that goal then needs to be communicated to the people who can affect change. When it comes to advocacy campaigns, there are two primary audiences that need to be incorporated into the strategy from the outset: the decision makers and the influencers.

The **decision makers** are those individuals who have the power to affect change. Advocacy programs can influence decision makers in both public and private funding organizations in the home country or region, as well as international funding organizations. They can shape local, state or national policy; provide research funding; or implement public health programs. While campaigns will need to take local context and political structures into consideration, as noted in FDI World Dental Federation's (FDI) guide to advocacy, these individuals may include "government ministers and their advisers, in particular minister of health and chief dental officer but, given the 'whole-of-government' focus, heads of other departments, parliamentarians (including members of the opposition), business leaders and other agencies that implement policy."⁹ Central to identifying these target audiences is also having a broader understanding of the role that each plays in providing funding or policy recommendations for research and health policy development.

UNDERSTANDING LOCAL POLITICAL DYNAMICS AND INSTITUTIONS

Remember that while certain concepts and messaging strategies may be utilized across advocacy campaigns, executing advocacy campaigns successfully depends largely on understanding the political system and decision-making structures in place, reaching the right policymakers, and having a thorough understanding of your issue, including where there are gaps and opportunities, who has spoken out on it, who benefits from it, and what traction, if any, has the issue gained in the media. Use all the resources at your disposal to having a solid grasp on your issue area, including:

- ▲ The Internet
 - (e.g., blog posts, online forums)
- ▲ Government reports and documents
- ▲ Newspaper articles, op-eds and periodicals
- ▲ Books

- ▲ Academic literature
- ▲ Professional associations or coalitions
- Individuals, including local or national government staff
- ▲ Statistics and data, including survey data

⁹ Oral Health and the United Nations Political Declaration on NCDs: A Guide to Advocacy: https://www.fdiworlddental.org/sites/default/files/media/images/oral_health_and_un_ political_dec_on_ncds.pdf The other key audience in advocacy campaigns is the **influencers**. The influencers are those individuals or groups that have the great potential to influence decision makers. Influencers may be public figures; the media; celebrities; well-known subject-matter experts; individuals with well-established relationships with key decision makers; or may represent a group, constituency or issue of importance to the decision maker(s).

When it comes to identifying target audiences, it is important to:

- Understand both allies and opponents that have the power to make change;
- ▲ Focus energy and resources on a few key targets;
- Understand the dynamics and relationships between decision makers and choose ones who may influence others; and
- ▲ Understand and leverage pre-existing relationships with key decision makers and influencers that exist in your advocacy network.

Below is a list of potential targets in dental, oral and craniofacial research decision making:

- President or Prime Minister
- ▲ Ministry of Health
- ▲ Ministry of Science
- ▲ Ministry of Education
- ▲ Ministry of Finance Officials
- ▲ Ministry of Foreign Affairs
- Members of Parliament
- Committees with jurisdiction over health funding
- Committees that oversee research funding

3. DO YOUR RESEARCH

The success of an advocacy campaign is largely contingent on work that is done beforehand, including analyzing the current political context in which you will be operating and conducting research on political processes and procedures, and the background of those you are trying to influence.

There is a saying coined by former United States Speaker of the House Tip O'Neill, "All politics is local." While originating in the United States, this phrase serves as an important reminder for any advocacy campaign. Politicians respond to issues that currently impact or will impact those they serve. When tailoring your message, do so under the frame of trying to understand the motivations and constituencies of those you are trying to influence—the issues of greatest importance to them, the goals they're trying to accomplish, the bills they have and have not supported—and then weigh how your efforts can help meet their needs. When available, local information and statistics are often the most effective tools for making your case.

UNDERSTANDING AND UTILIZING GOVERNMENT MOTIVATIONS

- 1. What are the government's overarching public policy goals?
- 2. How does your issue fit into the government's goals?
- **3.** Are there specific initiatives focused on your issue already in place, or are you advocating for new initiatives and policies to exist?
- **4.** Is there a way to frame your issue in the context of the government's overarching goals?
- **5.** Can you create a synergy through your issue that helps achieve your government's goals?
- **6.** Are there government officials interested in the issue who could serve as a potential champion?



When developing your plan of action, you may wish to consider the following elements:

▲ LEGISLATIVE AND POLITICAL PROCESSES

While political processes will vary from country to country, a key set of questions for all advocates to ask themselves is, "What is our (research funding) process, who can make this happen, and when should I insert myself to have the most influence on the process?" Establishing this frame of reference will allow campaign organizers to align their efforts with the political process and set themselves up for having the greatest impact.

▲ POLITICAL OR PROCEDURAL BARRIERS

Equally as important as knowing the best time to act during the political process is for advocates to identify any obstacles they may face while working to advance their goals. These challenges may include politicians who oppose a research area or policy program; a current policy; or a lack of funding.

▲ OPPORTUNITIES

Just as advocacy campaigns may face obstacles, they may also benefit from, or be able to capitalize on, circumstance. Campaign organizers should pay attention to what is happening both at home and abroad (e.g., trends in disease burden such as increased incidence or prevalence of oral disease) in case their issue area is related to a broader policy issue or an issue of importance to a decision maker.

▲ RELATED PAST EFFORTS

Advocates may also consider doing a scan to see if peer organizations or groups tried to conduct similar advocacy campaigns in the past. Learning about the past efforts of others may help inform which aspects of the campaign were successful and unsuccessful and where you could build upon previous work rather than starting anew.





4. DEVELOP THE MESSAGE AND A CLEAR "ASK"

Crafting the message that you plan to share with your target audience is among the most essential parts of an effective campaign. An overly complicated or technical message can hinder success.

It is also important to have a clear "ask" that will be relayed to your target audience. This can be as simple as "increase funding for oral health research," or it could encompass a more complex policy ask that is specific to a research policy in your country or region.

Key messages are the essence of a campaign; they are the points you want your audience to hear and to remember, and they should be incorporated in every stage of the campaign. While campaigns may want to tailor communications slightly depending on audience or communication channel, there are a number of characteristics of effective messages. Effective messages are:

Clear: absent of technical language and jargon.

Concise: able to be quickly delivered.

Consistent: repeated and reiterated until they're truly heard.

Compelling: those that appeal to authority, emotion and reason.

Credible: authentic and delivered by a reliable, trustworthy source.



¹⁰ "Adapted from Johnson Strategic Communications, Inc.": http://www.johnsonstrategic.com/StrategicCounsel.html

The lesson for me is that we must speak up. Scientists tend to become more and more specialized, to the point where it can be difficult to talk to other researchers, let alone the general public. I use my children as a sounding board. If they understand, I know I'm ready."

- TAMARA GALLOWAY, Ecotoxicologist, Exeter University, UK, Nature.com¹¹

CASE STUDY IADR's Advocacy During Minamata Convention on Mercury



Minamata Convention on Mercury: Text and Annexes, United Nations Environment Programme, *October 2013*

Strategic partnerships can play an important role in advocacy. They can enhance the evidence base upon which campaigns are built and provide an opportunity for knowledge-sharing among groups. From 2010-2015, the United Nations Environmental Program (UNEP) led an international negotiating process to develop the global legally-binding environmental treaty, the Minamata Convention on Mercury. As a wide-ranging environmental treaty to remove all sources of anthropogenic emissions and releases of mercury to land, water and air, dental amalgam was included in these discussions due to its mercury content. IADR partnered with other stakeholders on a strategy to phase-down(rather than phase-out or ban) the use of dental amalgam as a scientifically safe and effective dental restoration for dental professionals and their patients.

¹¹ Science Advocacy: Get Involved: https://www.nature.com/nature/journal/v540/n7634/ full/nj7634-611a.html

ISSUE

Dental caries is among the most common diseases throughout the world. Dental amalgam has a long history of efficacy and safety for restoring teeth damaged by caries. Therefore, it was problematic when some nonprofit groups called for a discontinuation of dental amalgam based on spurious claims of direct harm to human health during the negotiations leading up to the Minamata Convention on Mercury. Due to dental amalgam's durability, ease of handling, safety and low cost, IADR and other international dental organizations felt it was important to maintain access to the material, especially for low-resource countries, where access to technologies needed for newer restorative materials is inconsistent. It should be noted that this coalition of organizations also supported increased efforts of oral health promotion, thereby decreasing the need for any dental restoration, as well as best practices for the environmentally sound handling of amalgam waste.

ACTION

IADR worked closely with FDI World Dental Federation and other stakeholders to raise awareness of the potential public health consequences of an immediate dental amalgam ban. IADR and other dental stakeholders were supportive of the shared goal of protecting the environment from the negative impacts of mercury pollution and working towards a way to reduce the use of dental amalgam, while still preserving its availability for settings with no other feasible alternatives.

RESULT

In the final text of the treaty, the country signatories of the treaty agreed with IADR and its partners and secured an exception that would allow for a phase *down* rather than a complete phase *out* of dental amalgam, devising a comprehensive plan with environmental, research, and public health elements to facilitate the phase down. The treaty called for research into alternative restorative materials that could replicate the desirable properties of dental amalgam; the enhancement of national prevention efforts to decrease the need for restorations; increased education, training, and use of mercury-free alternatives; and the use of encapsulated dental amalgam and amalgam separators to capture and reduce mercury waste.

5. FORM PARTNERSHIPS AND BUILD COALITIONS

Relationships with influencers and outside partners—whether formal or informal, traditional or nontraditional—can contribute to an advocacy campaign's success. Collaborating with individuals, organizations, and alliances in the name of a shared policy goal allows you to:

- Amplify a campaign's message by reaching a broader group of people;
- Reduce the duplication of efforts;
- ▲ Combine resources; and
- ▲ Increase access to policy and political decision makers across sectors.

Potential partners for dental, oral and craniofacial researchers may include dentists, educators, public health practitioners, industry, cancer or other advocacy societies and organizations, patients, universities and educational institutions.

It is also important to think about possible partners outside of the oral health space, for example, infectious disease advocacy groups that might have a comorbidity with oral health issues, child health advocacy groups, smoking cessation organizations, etc.

In addition to specific partners who can assist in your advocacy campaign, think about coalitions that already exist that you can join to gather information and build relationships. Even outside of an organized advocacy campaign, it is important to maintain coalition memberships and engagement. Coalitions are also a great way to build community support for dental, oral and craniofacial research. Remember that it is equally important to educate other influencers to prepare them to help you in your advocacy efforts. Ensuring that oral health is represented at other community tables and coalitions (by you) will help to ensure that your messaging is carried as part of these bigger coalitions' goals—a rising tide lifts all boats!

21

CASE STUDY IADR Partners with FDI on Behalf of Oral Health

Strategic alliances can serve several purposes, including enhancing the credibility, impact, or even sustainability of an advocacy campaign. Coming together in pursuit of a common goal, IADR and FDI partnered in 2018 in hopes of providing a greater role for oral health in the recently concluded United Nations (UN) High Level Meeting (HLM) on Non-Communicable Diseases (NCDs):

ISSUE

As organizations committed to improving oral health worldwide, IADR and FDI were concerned that the Zero Draft of the UN High-Level Meeting on NCDs did not sufficiently integrate oral health perspectives into the broader NCD control and prevention policy framework. While oral diseases, including tooth decay and gum disease, are largely preventable, they rank among the most common and widespread diseases afflicting humankind and share many of the same risk factors and social determinants associated with more than 100 other NCDs.

ACTION

Recognizing that oral health is a health and development priority that the UN cannot afford to overlook, IADR and FDI joined forces to draft a letter that their members could send to decision makers, such as the president, prime minister, minister of health, or chief dental officer, recommending that the Zero Draft include a commitment to implement globally recommended fiscal policies, including price and tax measures on sugar, including sugar sweetened beverages, tobacco and alcohol as part of a comprehensive approach.

RESULT

There was no specific mention of oral diseases as an NCD, nor a common risk factor approach benefitting oral health in the final political document. While this initiative advocated for the importance of including oral health in the global conversations on NCDs, it was not successful. The IADR and FDI remain committed as ever to continuing this dialog. Not all of our advocacy efforts are going to be successful on the first round. The important point is to build on the contacts and relationships made, learn from the experience, and to have the tenacity to continue to advocate for such a worthy endeavor.



6. аст

Now that you have your goals, key messages, target audience, and some help from supporters, it is time to act. What are the methods you will use to reach out to your target influencers?



Send an email or a letter to influencers: remember to keep it brief and clear (see Chapter 5 of this toolkit for a template).



Call influencers on the phone: in many cases it might be hard to get through to them on the first try, but just like in an email, leave a brief voice message and ask them to return your call; if you do not hear back, call again in a few days. Be persistent.



Request a meeting: face-to-face meetings are one of the best ways to influence people and have the added benefit of providing you with an opportunity to pick up on social cues, such as body language, and to gauge someone's interest in your topic. If you do meet in person, be sensitive to time, and try to keep your discussion to around 30 minutes total (unless they offer more time!).



Write an op-ed or letter to the editor: If there is a story or relevant press coverage that discusses oral health or a broader health platform, take this opportunity to think about an op-ed in response. Remember to carefully consider who might be best to author or co-author the piece to ensure it gets good visibility.



Engage on social media: While we could develop an entire toolkit on how to use social media, there are a few simple things to keep in mind:

- ▲ Twitter and Facebook are great tools to engage with policymakers and other influencers; follow them and weigh in when they post things about health care.
- Remember to keep your social media presence professional—a few posts about your personal life are OK, but don't go overboard if you plan to use your platform as a tool for advocacy.
- ▲ Keep your posts short and to the point.
- ▲ Link to articles or other publications.
- ▲ Pictures are almost always better than words.

With any of these actions, remember a few **key advocacy tips** throughout your campaign:

- Start with "hello" an introduction and a friendly start to the conversation are always better than jumping right in with the ask.
- Contact information is essential make it easy for people to contact you with questions.
- ▲ Less is more refrain from leaving long reports or sending links to scholarly journal articles unless you are specifically asked for them.
- ▲ **Tell a story** instead of just presenting facts and figures, talk about a patient you treated or a personal experience you had to highlight the importance of your advocacy ask. Give real-world context to the problem.
- ▲ Make it personal think about how your message impacts the person you are talking to. In other words, what will make it resonate with him or her? Consider whether your message will be more meaningful framed in the context of family life or a current event. Remember, influencers are people!
- ▲ **Follow-up** remembering to reach back out is essential for relationship-building. If you meet, call, or write an influencer just once, your outreach could easily be forgotten.

DON'T UNDERESTIMATE THE POWER OF STORYTELLING



Tell stories. And think like a storyteller. Stories help people understand and empathize....The grantmaking process is all about one powerful story after another. Think about it: every grantee is on a journey. He or she wants to alleviate someone's suffering and has many obstacles to overcome to get there. It is the essence of any great story."

- LARRY BLUMENTHAL, How to Be an Effective Philanthropist in Eight Easy Steps¹²

¹² Blumenthal, Larry. Philanthropy News Digest, "How to Be an Effective Philanthropist in Eight Easy Steps, 2010: https://philanthropynewsdigest.org/commentary-and-opinion/ how-to-be-an-effective-philanthropist

7. EVALUATE YOUR PROGRESS

Evaluating advocacy can be challenging, as it does not lend itself to a scientific analysis of success. For example, during a given campaign, you may have contacted 50 policymakers and developed a sign-on letter with 100 signatures but did not achieve the desired policy outcome. However, you might have accomplished other, less tangible measures of success along the way. Some questions to consider at the end of your campaign could include:

- ▲ Did you educate policymakers about your issue?
- ▲ Did you cultivate a new champion who might be willing to take up your issue or cause the next time it surfaces for debate?
- ▲ Were you able to negotiate for a particular budget line to remain static rather than decrease?

These are all examples of success. Furthermore, do not overlook the contacts you've made through your efforts; these are often a first indicator of your successes.

MULTILATERAL AND NON-GOVERNMENTAL ORGANIZATIONS



For advocacy efforts that span borders, other actors to consider are multilateral and non-governmental organizations. While these groups operate independently, they are often supported by governments, and part of their goals may align with those of one or more states. This section will outline the purpose of these groups and how they can be both targets and players in advocacy efforts. **Multilateral organizations** are formed by a group of individual nations around a main focus or issue area and usually receive operational funding from its member governments. These partnerships may be international, such as the United Nations (UN) and the North Atlantic Treaty Organization (NATO), or they may be regional, such as the Association of Southeast Asian Nations (ASEAN). Multilateral organizations are often effective facilitators of global priority issue areas, whether development, human rights, or security.

Non-governmental organizations, or NGOs, though a broad description, are non-profit, citizen driven organizations that operate independent of any government, although they may receive some government funding. These groups, which include entities such as Doctors Without Borders, CARE, and Oxfam, are commonly based around a singular focus or mission—economic growth or welfare issues, such as health or education.

These groups not only connect with the public and societal groups, but they regularly engage with each other. NGOs, which represent the interests of civil society, can inform multilateral bodies on issues of relevance, whereas multilateral organizations help develop and execute priorities for member states. While individual citizens are often not equipped to directly engage with multilateral bodies, they can often do so through NGOs. As in all stages of your campaign, do your research to determine how you can be most effective.

From a partnership perspective, both the UN and the WHO have formal mechanisms in place for engaging with civil society organizations, and in both cases, the voices of individuals play an important role. Groups often want to work with patients, health care providers, or other affected populations to ensure their perspectives are considered, elevating these issues on an international stage. To facilitate engagement with these groups, WHO developed the "Framework of engagement with non-State actors"¹³ handbook that is intended to guide non-state actors—such as NGOs, private sector entities, and philanthropic foundations—in working with the WHO.

Beyond bringing forth stakeholder groups, you can also engage in hopes of influencing an entity's policy. For example, imagine there is an international resolution from the WHO focused on oral health, but it excludes research or evidence-based policy recommendations, or the designated targets for oral health do not meet the needs of the dental, oral, and craniofacial research community. In this case, the WHO and its regional offices could be key targets for an advocacy campaign focused on oral health. This would represent an ideal opportunity to weigh in on the WHO process and work to impact the outcome of the resolution.

¹³ http://www.who.int/about/collaborations/non-state-actors/en/

While there are a number of NGOs and multilateral actors you may wish to try to involve in your advocacy efforts, here are some of the entities with at least a partial health focus that you may wish to consider, either as a partner or for information that you can utilize to bolster your own efforts:

United Nations (UN): International organization founded in 1945 at the end of World War II with 193 "member states." Guiding the UN's mission is its charter, which outlines the ability of the UN to tackle "issues confronting humanity in the 21st century, such as peace and security, climate change, sustainable development, human rights, disarmament, terrorism, humanitarian and health emergencies, gender equality, governance, food production, and more."¹⁴ The UN is headquartered in New York, United States, and has a number of individual agencies, such as the United Nations Children's Fund (UNICEF) that focus on key issue areas, including the environment, food security, agriculture, and health.

World Health Organization (WHO): Main organization responsible for international health issues. Part of the UN system, the WHO is governed by the World Health Assembly (WHA), a delegation of WHO member states. The WHO's agenda, which may involve hosting meetings or international for or producing resolutions, is set annually by the WHA. The WHO has six regional offices focused on Africa, the Americas, South East Asia, Europe, the Eastern Mediterranean, and the Western Pacific. The regional office for the Americas, for example, is the Pan American Health Organization (PAHO), which is headquartered in Washington, D.C., in the United States.

World Bank: Global partnership working to "end extreme poverty and promote shared prosperity in a sustainable way."¹⁵ The World Bank Group has 189 member countries with offices in more than 130 locations and focuses on global and local development challenges, from health, education, and gender to climate change and energy.

¹⁴ Overview, United Nations (2018):

http://www.un.org/en/sections/about-un/overview/index.html

¹⁵World Bank (2018): http://www.worldbank.org/

REGIONAL ORAL HEALTH INFORMATION



This section includes oral health data, categorized by global regions. These oral health statistics may be utilized in meetings to share the oral health needs for a specific area or to shed light on where future or further research is needed.¹⁶ A good resource for international data on oral health is the FDI Data Hub for Global Oral Health.¹⁷

Note: The information contained in this section is intended to serve as a snapshot of the funding opportunities available in different countries; it is not comprehensive and does not capture every country. Additionally, the information provided herein may become out of date quickly. IADR intends for this toolkit to serve as a living document, so please email any updates on the data to research@iadr.org.

¹⁶ If you have data or statistics that are not included here and would like to contribute to the information provided for any region, please contact.

¹⁷ FDI Data Hub For Global Oral Health: http://datahub.fdiworlddental.org/

ASIA

- ▲ Cleft lip/cleft palate rates of 0.82–4.04 per 1,000 live births;¹⁸
- Oral cancer is among the three most common types of cancer, relating directly to smoking, use of smokeless tobacco, and alcohol consumption;¹⁹
- ▲ Greater than 50% of males in Indonesia, China, and Malaysia are smokers.²⁰

Japan



In 2005 **82% of men and women** aged 35–44 have periodontal disease, and **5% of those** have severe periodontal disease;



12-year-old children, on average, have at least **1.4 teeth** that are decayed, missing, or filled (DMFT);



In 2016 there was an average of **0.2 DMFT** per person;²¹



In 2012 lip and oral cavity cancer occurred in **8,306 people** (6.6% of the population), which led to **3,994 deaths**²²;



Cleft lip/cleft palate rate of **16.04 per 1,000** live births.²³



- ¹⁸ Petersen, P. E. "Oral Health." International Encyclopedia of Public Health4 (2008): 677-85.
- ¹⁹ Petersen, P. E. "Oral Health." International Encyclopedia of Public Health4 (2008): 677-85.
- ²⁰ The Burden of Cancer in Asia: Pfizer, 2002. https://www.pfizer.com/files/products/ cancer_in_asia.pdf
- ²¹ Oral Health Database: https://www.mah.se/CAPP/Country-Oral-Health-Profiles/WPRO/

²² A. Tiyuri, A. Mohammadian-Hafshejani, E. Iziy, H.S. Gandomani, H. Salehiniya. (2017). The incidence and mortality of lip and oral cavity cancer and its relationship to the 2012 Human Development Index of Asia. Biomedical Research and Therapy. 4 (2): 1147-1165.

²³ Global Registry and Database on Craniofacial Anomalies: http://www.who.int/genomics/ anomalies/en/ZZ-Annex.pdf



POTENTIAL FUNDING SOURCES

Agency for Medical Research and Development (AMED):

The government of Japan set in place a plan that calls for achieving medical care that meets the expectations of the people and society and provided \$1.4 billion for the AMED research and development budget.²⁴ "The government will undertake initiatives aimed at gaining a precise understanding of the needs of patients—including from the perspective of quality of life after treatment—and of citizens and society as a whole in relation to a diverse range of conditions. These include diseases of the oral cavity which are strongly suspected of being linked to lifestyle-related diseases." The AMED will strive to promote integrated R&D in the field of medicine, from basic research to clinical trials, focusing on nine interrelated areas including regenerative medicine and oncology. Over the next five years Japan will seek to streamline research funding through the AMED process as opposed to researchers seeking funding from three separate ministries.

Japan Society Promotion of Science (JSPS): "JSPS advances scientific research through its Grants-in-Aid for Scientific Research and other funding programs; fosters young researchers through its Research Fellowships for Young Researchers and other researcher development programs, promotes international scientific exchange, and supports university reform and globalization." There are dental program officers who are in charge of selection of projects and in FY14, JPS funded eight dental and craniofacial related projects.²⁵

Ministry of Health, Labor, & Welfare of Japan Project Research Fund: This fund is used for researchers who are looking to advance the medical and dental fields. Currently, the ministry is seeking applications to fund regenerative medicine technologies. Their continued effort in this area is attracting global attention. Practical application of regenerative medicine requires development of a system for ensuring the safety of regenerative medicine to enable advancing future research development.²⁶

²⁴ Japanese Agency Looks to Remap Country's Research Funding Landscape: https://www. genomeweb.com/regulatory-news/japanese-agency-looks-remap-countrys-researchfunding-landscape

²⁵ Japan Society for the Promotion of Science: http://www.jsps.go.jp/english/aboutus/data/ brochure14-15_e.pdf

²⁶ Ministry of Health, Labour and Welfare Service Guide 2017: http://www.mhlw.go.jp/english/org/pamphlet/dl/pamphlet-about_mhlw.pdf

Korea



A national survey from 2012–2014 found that approximately **15%** of South Koreans had periodontal disease;²⁷



In 2012 12-year-old children, on average, had **1.8** teeth that were decayed, missing, or filled (DMFT);



In 2012 oral cancer occurred in **1,575 people** (3.2% of the population), leading to **517 deaths**.

POTENTIAL FUNDING SOURCES

National Research Foundation of Korea (NRF): NRF aims to connect researchers with a support system to further their research, which has proven conducive for producing creative and challenging research: "[T]he NRF will not become complacent in the face of past successes. Our wish is to serve as the foundation for the new quantum jump in Korea. This year, we hope to continue in our ceaseless efforts towards this goal."

Korea Health Industry Development Institute:

This program, established in 1999 by the Korean government, charged with strengthening "the global competitiveness of the national health industry by providing comprehensive and professional support programs to promote/improve the national health industry, and contribute to the people's health."²⁸ One of the many projects this project encompasses is support health and medical service research and development public policy development. In addition, it establishes a plan for international collaboration on health and medical service research.

²⁷ Association Between Oral Health Behavior and Periodontal Disease among Korean Adults: Han, 2017. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5319547/

²⁸ Korea Council of R&D Funding Agencies, Korea Health Industry Development Institute: http://corfa.or.kr/eng/main/?skin=intro_summary05.htm

China

In 2012 **100% of men and women** aged 35–44 and aged 65–74 had periodontal disease; **13% of the younger group** had severe periodontal disease, **28% of the older group** had severe periodontal disease;²⁹



In 2016 12-year-old children in Sichuan Province on average had **0.9 teeth** that are decayed, missing, or filled (DMFT);³⁰



In 2015 there were an estimated **48,000 new lip and oral cancer cases** and **22,000 oral cancer deaths**. Men account for roughly two-thirds of the new cases and deaths.³¹

POTENTIAL FUNDING SOURCE

National Natural Science Foundation of China: Founded 25 years ago to promote innovation and to provide a mechanism for fair competition, NSFC's establishment gave more power to individual scientists, and represented a major advance in the move towards democracy in science. Basic research funding via NSFC reached 9,465 million RMB in 2010."³²

Science & Technology Planning Project of Guangdong Province, China: This entity realizes that research is crucial to social and economic development. It works to draft policies and measures to promote knowledge and technology innovation in the province. In addition, it plans facility support for scientific research with government policies.³³



- ²⁹ WHO Database: https://www.dent.niigata-u.ac.jp/prevent/perio/perio.html
- ³⁰ Dental Caries: https://www.mah.se/CAPP/Country-Oral-Health-Profiles/WPRO/China/ Oral-Diseases/Dental-Caries/
- ³¹ Chen, W., Zheng, R., Baade, P. D., Zhang, S., Zeng, H., Bray, F., Jemal, A., Yu, X. Q. and He, J. (2016), Cancer statistics in China, 2015. CA: A Cancer Journal for Clinicians, 66: 115-132. doi:10.3322/caac.21338
- ³² Feng, Zhi-hua, and Tina C. Pei. "The '10 Billion' Cake: National Natural Science Foundation of China." *Journal of Thoracic Disease* 3.3 (2011): 213–216. *PMC*.
- ³³ Guangdong Science and Technology Department: http://www.gdstc.gov.cn/eng/mission.html

SOUTH AMERICA

Brazil³⁴



15.3% of Brazilian adults had moderate-severe periodontal disease in 2013, with **5.8%** of all Brazilian adults suffering from severe periodontal disease in 2013;



In 1988 **99%** of 34–44-year-old Brazilians had periodontal disease, **24%** had severe periodontal disease;



In 2010 12-year-old children had on average **2.1 teeth** that were decayed, missing, or filled (DMFT);



In 2012 oral cancer occurred in **10,439 people** (5.3% of the population) leading to **4,082 deaths**.

POTENTIAL FUNDING SOURCES

South American Institute of Government in Health (ISAGS): ISAGS, a center for research and debate on health development public policy in the South American countries, was created in 2010. The intergovernmental organization is headquartered in Rio de Janeiro and its activities involve building leadership and supporting healthy systems.

The Brazilian National Research and Development Council (CNPq):

CNPq is an organization of the Brazilian federal government, linked to the Ministry of Science and Technology. Its aim is to finance research projects that contribute to the production of scientific knowledge and the generation of new opportunities of growth for the country. One example of these growth opportunities is CNPq's 'Productivity in Research' grant, an 'Individual grant' modality with the purpose of distinguishing outstanding Brazilian researchers whose scientific production has met criteria established by the CNPq and its Advisory Committees.³⁵

³⁴ Ten Years of a National Oral Health Policy in Brazil: Innovation, Boldness, and Numerous Challenges: https://www.researchgate.net/publication/281337481

³⁵ Scarpelli, Ana Carolina, Sardenberg, Fernanda, Goursand, Daniela, Paiva, Saul Martins, & Pordeus, Isabela Almeida. (2008). Academic trajectories of dental researchers receiving CNPq's productivity grants. *Brazilian Dental Journal*, 19(3), 252-256.

The State of São Paulo Research Foundation (FAPESP): FAPESP

promotes scientific and technological research in all areas of knowledge: Biological Sciences, Health Sciences, Physical Sciences and Mathematics, all fields of Engineering, Agrarian Science, Applied Social Sciences, Linguistics and Humanities and the Arts. The fellowships are intended for graduate and post-graduate students in teaching and research institutions in the State of São Paulo. Financial awards are intended for researchers in teaching and research institutions in the State of São Paulo who hold a minimum qualification of doctorate.³⁶ Besides funding research in all fields, the foundation supports large research programs in Biodiversity, Bioenergy, Global Climate Change, and in Neurosciences."³⁷

A Fundação de Amparo à Pesquisa e ao Desenvolvimento Científico e Tecnológico do Maranhão (FAPEMA): FAPEMA is linked to the Ministry of Science, Technology and Innovation, and it seeks to promote human development through scientific research and technological innovation. FAPEMA receives direction from national policy, and its actions are structured into four areas: "More Science, More Innovation, More Training and Popularization of Science."³⁸

Coordination for the Improvement of Higher Education Personnel (CAPES): CAPES is a foundation within the Ministry of Education in Brazil whose central purpose is to coordinate efforts to improve the quality of Brazil's faculty and staff in higher education through grant programs.³⁹

³⁶ São Paulo Research Foundation: http://www.fapesp.br/en/

³⁷ Zentrum für Soziale Innovation: https://www.zsi.at/en/object/partner/4128

³⁸ FAPEMA: https://www.fapema.br/index.php/institucional/

³⁹ CAPES: https://www.iie.org/en/Programs/CAPES/About

EUROPE⁴⁰

- ▲ Oral health ranges greatly, with 20–90% of European 6-year-olds having dental caries;
- Severe periodontal disease is found in 5–20% of middle-aged (35–44 years) adults in Europe, and up to 40% of older people (65–74 years);
- ▲ In Europe, the incidence of oral cancer ranges from 5 to 10 cases per 100,000 people;
- ▲ The prevalence rate of older people (65–74 years) having lost all their natural teeth varies from 5% to 51%;
- ▲ Birth defects such as cleft lip and palate occur in about one per 500–700 of all births. This rate varies substantially across different ethnic groups and geographical areas.

United Kingdom⁴¹

In

In 2009, roughly **80%** of people in the UK over 16 years old had some sign of periodontal disease;⁴²



12-year-old children have on average have at least **0.7 teeth** that are decayed, missing, or filled (DMFT) in 2006;⁴³

Each year about **7,800** new cases of oral cancer are diagnosed in the UK, approximately one case for every **8,500 people**.⁴⁴

- ⁴¹ Adult Dental Health Survey 2009 Summary report and thematic series, NHS England: https://digital.nhs.uk/data-and-information/publications/statistical/adult-dental-healthsurvey/adult-dental-health-survey-2009-summary-report-and-thematic-series
- ⁴² OECD (2009), "Dental health among children", in Health at a Glance 2009: OECD Indicators, OECD Publishing, Paris: https://doi.org/10.1787/health_glance-2009-12-en
- ⁴³ Improving Dental Care and Oral Health—A Call to Action Evidence Resource Pack: https://www.england.nhs.uk/wp-content/uploads/2014/02/dental-info-pack.pdf
- ⁴⁴ About Mouth and Oropharyngeal Cancer: https://www.cancerresearchuk.org/about-cancer/mouth-cancer/about

⁴⁰ WHO Data and Statistics: http://www.euro.who.int/en/health-topics/disease-prevention/ oral-health/data-and-statistics

POTENTIAL FUNDING SOURCES AND RESEARCH INITIATIVES

Horizon Europe: Horizon Europe will build on the efforts of Horizon 2020, a research and innovation program of the European Union. The program will "continue to drive scientific excellence through the European Research Council (ERC) and the Marie Skłodowska-Curie fellowships and exchanges, and will benefit from the scientific advice, technical support and dedicated research of the Joint Research Centre (JRC), the Commission's science and knowledge service."⁴⁵ In addition to original efforts, Horizon Europe will also include new features, including the Europe Innovation Council, which is intended to serve as a one-stop shop to bring disruptive and breakthrough innovations from lab to market applications, and help start-ups and small and medium enterprises (SMEs) scale up their ideas.

European Research Council: Formed in 2007, this council seeks to fund both established and the next generation of researchers. The ERC states that their "approach allows researchers to identify new opportunities and directions in any field of research, rather than being led by priorities set by politicians. This ensures that funds are channeled into new and promising areas of research with a greater degree of flexibility." ERC grants "are awarded through open competition to projects headed by starting and established researchers, irrespective of their origins, who are working or moving to work in Europe. The sole criterion for selection is scientific excellence. The aim here is to recognize the best ideas and confer status and visibility on the best brains in Europe, while also attracting talent from abroad."⁴⁶

UK Clinical Research Network: This organization serves as an infrastructure to the countries of the United Kingdom. It was founded in 2004 with the aim of changing the research environment in in the UK. UKCRN and its stakeholders provide unique strategic direction and oversight to key issues in the UK.⁴⁷

⁴⁵ http://europa.eu/rapid/press-release_IP-19-1676_en.htm

⁴⁶ European Research Council: http://erc.europa.eu/about-erc/mission

⁴⁷ UK Clinical Research Collaboration:

http://www.ukcrc.org/about-the-ukcrc/what-is-the-ukcrc/

National Institute for Health Research (NIHR): This unique and innovative institute aims to improve the health and wellbeing of the United Kingdom through research. The NIHR has adopted four pillars to enact on that mission: Infrastructure, Faculty, Research, and Systems. Their website also is constantly updated with possible funding grants being offered.

NIHR Funding Opportunities available at: https://www.nihr.ac.uk/ funding-and-support/funding-opportunities/

Swiss National Research Foundation: This foundation, mandated by the Swiss Confederation to fund basic research and promote young scientists in Switzerland, centers on strengthening Swiss research through the following strategies: Support high-quality research as well as researchers in their quest for excellence. Bring research funding closer into line with the researchers' needs. Support the spread of knowledge in society, the economy and politics and demonstrate the value of research."⁴⁸

Netherlands Organization for Scientific Research (NWO): NWO's mission is to advance world-class scientific research that has scientific and societal impact. The NWO does this by facilitating "curiosity-driven disciplinary, interdisciplinary and multidisciplinary research." Its strategic plan for 2019-2022 emphasizes NWO's role in making connections within and between science and society.⁴⁹



⁴⁸ Swiss National Science Foundation: http://www.snf.ch/en/theSNSF/profile/strategy/ Pages/default.aspx

⁴⁹ Netherlands Organisation for Scientific Research: http://www.nwo.nl/en/about-nwo/strategy

AFRICA

- ▲ Dentist to population ratio is approximately 1:150,000, in contrast to approximately 1:2000 in most industrialized countries;⁵⁰
- High incidence of NOMA;
- ▲ High incidence of fluorosis from diet.⁵¹

South Africa52

100% (n=69) of men and women aged 35–44 have periodontal disease, 1984; **35%** of those have severe periodontal disease, 1984;



12-year-old children on average have at least **1.1 teeth** that are decayed, missing, or filled (DMFT);

No data available on oral cancer incident and mortality rates.

RESEARCH PROMPTED BY THE AFRICAN UNION'S AFRICA HEALTH STRATEGY

The Africa Health Strategy, an updated strategy for the years 2016-2030, is based on several continental and global health policy commitments and is intended to offer a platform to help the African Union's Member States create better performing health sectors, address challenges, draw on lessons learned and more. In its strategy, the AU makes reference to health research and innovation, which may spur research grants across the continent: "[D]ata from health research and innovation must be collected and analyzed to inform policy and decision-making at all levels of the healthcare system. Member States should encourage locally driven and financed research through the empowerment of local research institutions, setting up of innovation hubs and allocation 2% of the national budget for research and innovation Strategy for Africa 2014-2024."

- AFRICA HEALTH STRATEGY: 2016-2030⁵³

 ⁵⁰ Petersen, P. E. "Oral Health." *International Encyclopedia of Public Health4* (2008): 677-85. Web.
 ⁵¹ Ibid., 40.

⁻ IDIU., 40

⁵² Ibid., 6.

⁵³ https://au.int/sites/default/files/documents/24098-au_ahs_strategy_clean.pdf

South African National Research Foundation: One of the pillars of this foundation is the focus on world-class research. It recognizes that research is not only important for the present generation, but also for future generations: "As an entity of the Department of Science and Technology (DST), the NRF promotes and supports research through funding, human resource development and the provision of National Research Facilities in all fields of natural and social sciences, humanities and technology."⁵⁴

Real Life Example: The Development of a Craniofacial Anomalies Network: Dr. Butali directs the African Craniofacial Anomalies Network, a collaboration between scientists in Ghana, Ethiopia, Kenya, Nigeria, and Rwanda. His research, "Genetic Studies of Non-syndromic Clefts in Populations of African Descent," is currently funded through a K99/R00 award from the United States-based National Institute of Dental and Craniofacial Research.⁵⁵

⁵⁴ http://www.nrf.ac.za/about-nrf/history

55 https://www.dentistry.uiowa.edu/azeez-butali

NORTH AMERICA

United States of America



18.6% of children aged 5–19 years with untreated dental caries (2011-2014);⁵⁶



31.6% of adults aged 20–44 with untreated dental caries;

Of those without a dental visit in the past 12 months, **59%** cite cost as the reason for not visiting the dentist more frequently;⁵⁷



1 in 5 low income adults say their mouth and teeth are in poor condition.

POTENTIAL FUNDING SOURCES

U.S. Department of Health and Human Services (HHS): HHS is comprised of 11 operating divisions, including eight agencies in the U.S. Public Health Service and three human service agencies, that administer a wide range of health and human services and conduct critical research for the nation. There are several research agencies within HHS, including:

National Institutes of Health (NIH): A part HHS, the NIH is the largest biomedical research agency in the world. The agency's mission is to "seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability."⁵⁸ The NIH conducts its own research through its Intramural Research Program, but also provides major research funding to non-NIH research entities through its Extramural Research Program. The NIH has 27 separate institutes and centers of different biomedical disciplines, including the National Institute of Dental and Craniofacial Research (NIDCR), the National Cancer Institute (NCI) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

⁵⁶ https://www.cdc.gov/nchs/fastats/dental.htm

⁵⁷ "Oral Health and Well-Being in the United States," ADA Health Policy Institute: https:// www.ada.org/~/media/ADA/Science%20and%20Research/HPI/OralHealthWell-Being-StateFacts/US-Oral-Health-Well-Being.pdf?la=en

⁵⁸ Mission and Goals, National Institutes of Health: https://www.nih.gov/about-nih/whatwe-do/mission-goals



- ▲ Agency for Healthcare Research and Quality (AHRQ): AHRQ's mission is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within HHS and with other partners to make sure that the evidence is understood and used. AHRQ's goals include keeping patients safe, helping doctors and nurses improve quality and developing data to track changes in the health care system.⁵⁹
- ▲ Health Resources and Services Administration (HRSA): HRSA provides health care to those who are geographically isolated, or economically or medically vulnerable. In addition to helping those in need of care, HRSA also supports the training of health professionals, the distribution of providers to areas where they are needed most and improvements in health care delivery.⁶⁰

National Science Foundation: An independent federal agency, the National Science Foundation (NSF) holds a mission to "promote the progress of science; to advance the national health, prosperity, and welfare; to secure the national defense..."⁶¹ NSF is the funding source for approximately 24 percent of all federally supported basic research conducted by America's colleges and universities, in fields spanning mathematics, computer science and the social sciences.

Patient Centered Outcomes Research Institute (PCORI):

PCORI is an independent, non-governmental organization authorized in 2010 via the Patient Protection and Affordable Care Act. PCORI's mission is to help people make informed health care decisions and works to improve health care delivery and outcomes by producing evidence-based information that comes from research guided by patients, caregivers and the broader health care community. As part of that mission, PCORI supports clinical effectiveness and decision science and well as health care delivery and disparities research.

⁵⁹ https://www.ahrq.gov/cpi/about/index.html

⁶⁰ https://www.hrsa.gov/about/index.html

⁶¹ https://www.nsf.gov/about/

Mexico



76.7% of adults aged 65–69 years old have poor oral hygiene;⁶²



Prevalence of caries in adults over 40 years of age is more than **97%**;

60-70% of Mexicans aged over 65 have few or no teeth.63

POTENTIAL FUNDING SOURCES

National Council on Science and Technology (CONACYT):

CONACYT aims to promote the scientific development and technological modernization of Mexico through "developing high level human resources, promoting and maintaining specific research projects, and disseminating scientific and technological information."⁶⁴ To address Mexico's research, and science and technology priorities, CONACYT established a network of 27 research centers, including the Yucatan Center for Scientific Research and the Institute for Scientific and Technological Research of San Luis Potosi.

⁶² https://www.researchgate.net/publication/313125208_The_paradigm_of_oral_health_in_Mexico

43

63 https://www.who.int/bulletin/volumes/83/9/infocus0905/en/

64 https://twas.org/partner/national-council-science-and-technology-mexico



Canada



23.6% of children with at least one decayed tooth⁶⁵;

The average number of decayed, missing, or filled teeth (per child) is **2.5**;



6.4% of adults with no natural teeth.

POTENTIAL FUNDING SOURCES

Canadian Institutes of Health Research (CIHR): Composed of 13 Institutes and part of the Health Portfolio, CIHR is Canada's federal funding agency for health research. CIHR is an independent agency and is accountable to Parliament through the Minister of Health. The agency's mission is to create new scientific knowledge and to enable its translation into improved health, more effective health services and products, and a strengthened Canadian health care system.⁶⁶ One of the 13 CIHR institutes is the Institute of Musculoskeletal Health and Arthritis (IMHA), which is the hub for strategic initiatives in musculoskeletal, skin and oral health research in Canada. IMHA's mandate is to support ethical and impactful research to enhance active living, mobility and oral health, and to address the wide range of conditions related to bones, joints, muscles, connective tissue, skin and teeth.⁶⁷

National Sciences and Engineering Research Council of Canada (NSERC): The NSERC "supports university students in their advanced studies, promotes and supports discovery research, and fosters innovation by encouraging Canadian companies to participate and invest in postsecondary research projects."⁶⁸ The agency supports

the Discovery Grants, thematic research and more.

Canadian Institute for Military & Veteran Health Research (CIMVHR): The mission of CIMVHR is "to enhance the lives of Canadian military personnel, Veterans and their families by harnessing the national capacity for research."⁶⁹ The agency provides infrastructure to allow more of Canada's military, veteran and family health research requirements to be met; improve the accessibility of military, veteran and family health research; and collaborate with stakeholders on efforts to increase research and improve knowledge translation activities.

⁶⁵ https://www.cda-adc.ca/stateoforalhealth/flip/#1

⁶⁶ http://www.cihr-irsc.gc.ca/e/37792.html

⁶⁷ http://www.cihr-irsc.gc.ca/e/8603.html

⁶⁸ http://www.nserc-crsng.gc.ca/NSERC-CRSNG/Index_eng.asp

⁶⁹ https://cimvhr.ca/about-us/

TOOLS & TEMPLATES YOU CAN USE



SECTIONS

Α.	IADR Regions, Divisions, and Sections	46
Β.	IADR Scientific Groups and Networks	46
C.	Sample Template Letter to Decision Makers	47
D.	Template Letter to Influencers or Decision Makers	50
E.	Template Funding Request Fact Sheet	51

SECTION A: IADR REGIONS, DIVISIONS AND SECTIONS

Africa/ Middle East Region

East & Southern Africa Division Egyptian Section Iranian Division Jordanian Section Kuwaiti Division Lebanese Section Libyan Section Nigerian Division Saudi Arabian Division South African Division Sudanese Section Syrian Section Tunisian Section United Arab Emirates Section

Asia/Pacific Region

Australian/New Zealand Division Chinese Division Indian Division Japanese Division Korean Division Mongolian Section Pakistan Section Southeast Asian Division

Latin American Region

Argentine Division Brazilian Division Caribbean Section Chilean Division Colombian Division Costa Rican Section Ecuadorian Section Guatemalan Section Panamanian Section Paraguayan Section Peruvian Division Uruguayan Division Venezuelan Division

North American Region

American Division Canadian Division Mexican Division

Pan European Region

PER-IADR Website British Division Continental European Division Irish Division Israeli Division Russian Section Scandinavian Division

SECTION B: IADR SCIENTIFIC GROUPS AND NETWORKS

Behavioral, Epidemiologic and Health Services Research Cariology Research Clinical and Translational Science Network Craniofacial Biology Research Dental Anesthesiology Research Dental Materials Research Diagnostic Sciences Research e-Oral Health Network Education Research Evidence-based Dentistry Network Geriatric Oral Research Global Oral Health Inequalities Research Network Implantology Research International Network for Orofacial Pain and Related Disorders Methodology (INfORM) Microbiology/Immunology Research Mineralized Tissue Research Network for Practice-based Research Neuroscience Research Nutrition Research Oral and Maxillofacial Surgery

Oral Health Research Oral Medicine and Pathology Orthodontics Research Pediatric Oral Health Research Periodontal Research Pharmacology/Therapeutics/ Toxicology, Prosthodontics Research Pulp Biology and Regeneration Salivary Research Stem Cell Biology Research Student Training and Research (STAR) Network Women in Science Network

SECTION C: SAMPLE LETTER TO DECISION MAKERS

The "Sample Letters in this section is based on the U.S. system of government. Those engaging in advocacy campaigns are welcome to adapt all or part of these letters for use in their respective regions and countries, if appropriate.

In the United States, Congress is responsible for developing the federal government's annual budget. Their work involves setting the top-line spending level as well as determining how the funds will be distributed across government departments, agencies, and programs. While Congress ultimately holds "the power of the purse," stakeholders and constituents that members of Congress represent can weigh in on their respective funding priorities for the year.

As one example, the American Association for Dental Research (AADR) each year asks Congress to support federal research agencies and programs, particularly those that support oral health research, such as the National Institutes of Health (NIH) and its National Institute of Dental and Craniofacial Research (NIDCR). AADR makes these requests by meeting with congressional offices and through sign-on letters from the Friends of NIDCR, a coalition that AADR maintains. The letter on the following page is one of the letters the Friends of NIDCR submitted to members of Congress in 2018.

RIENDS OF National Institute of Dental and Craniofacial Research

April 6, 2018 The Honorable Thad Cochran Chairman Committee on Appropriations U.S. Senate Washington, DC 20510

The Honorable Patrick Leahy Vice Chairman Committee on Appropriations U.S. Senate Washington, DC 20510 The Honorable Roy Blunt Chairman Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies U.S. Senate Washington, DC 20510

The Honorable Patty Murray Ranking Member Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies U.S. Senate Washington, DC 20510

Dear Chairman Cochran, Vice Chairman Leahy, Chairman Blunt, and Ranking Member Murray:

The undersigned organizations, as supporters of the Friends of National Institute of Dental and Craniofacial Research (FNIDCR), respectfully request that as you and your colleagues draft the Labor, Health and Human Services, Education and Related Agencies appropriations legislation for fiscal year (FY) 2019 that you fund the National Institutes of Health (NIH) at **at least \$39.3 billion**, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives, and the National Institute of Dental and Craniofacial Research (NIDCR) at **\$492 million**.

NIDCR, founded in 1948 to address shortfalls in military readiness due to recruits' poor oral health, is now the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial (skull and face) health. Over the years, the Institute's portfolio has expanded, and oral health researchers' discoveries, innovations and public health initiatives, including fluoride in water, toothpaste and varnish and dental sealants, have led to a precipitous drop in tooth decay among children and resulted in more Americans keeping more of their teeth for longer.⁷⁰ Since the 1950s, estimates reveal that the **total federal investment in NIH-funded oral health research has saved the American public at least \$3 for every \$1 invested**.⁷¹

This year marks NIDCR's 70th anniversary. Yet, even with the Institute's myriad contributions to citizens' oral and overall health, oral diseases and conditions remain a prevalent and costly part of our society, and troubling disparities still persist. For example, cavities, though largely preventable, remain the most common chronic condition of children (aged 6 to 11) and adolescents (aged 12 to 19), and oral disorders are the seventh greatest health expenditure among U.S. adults. Furthermore, Hispanic and non-Hispanic black children are more likely to suffer from untreated dental caries.⁷² At a macro level, in 2017 the United States spent more than \$129 billion on dental and oral health care and recent projections suggest that annual U.S. spending on dental care will reach \$192 billion by 2026.⁷³

Our society benefits when we capitalize on dental, oral and craniofacial research—both in terms of cost savings and overall well-being—and sufficient federal funding will allow NIDCR to continue addressing the nation's most pressing public health issues in order to create a healthier future. Right now, NIDCR-funded researchers are actively combatting the dual crises of opioid abuse and chronic pain by researching prescription drug decision-making and pain biology and management. The Institute has also made strategic investments in regenerative medicine to replace bone and oral tissues lost or damaged by cancer and other diseases or trauma, as well as investments aimed at eliminating oral health disparities by supporting projects that investigate their social, behavioral and genetic underpinnings. Additionally, NIDCR is fortifying the future of the field by training a diverse workforce that harnesses the talents and potential of the U.S. population.

The funding requested by the Friends of NIDCR for FY 2019 will allow this Institute to support the best science; conduct research that will move us toward precision health care and help overcome health disparities; and ensure a strong health research workforce dedicated to improving dental, oral and craniofacial research. Since its inception through the present, NIDCR has been improving the health of our nation, reducing the societal costs of dental care and providing us with the evidence base needed to improve care. Increasing funding for NIDCR is the optimal way to ensure its life-changing and cost-saving initiatives and innovations continue.

We look forward to working with you to ensure the highest possible funding level for NIDCR is enacted this year. We greatly appreciate your leadership thus far to make this a reality and hope to see your continued support for NIH and NIDCR in FY 2019 spending legislation.

Thank you for considering our recommendations. If you have any questions or require additional information, please contact Lindsey Horan at lhoran@aadr.org.

Sincerely,

Academy of Dentistry International Adenoid Cystic Carcinoma Research Foundation American Association for Dental Research American Association of Oral & Maxillofacial Surgeons American Behcet's Disease Association ((ABDA) American Dental Association American Dental Education Association Dental Trade Alliance East Carolina University School of Dental Medicine Eastman Institute for Oral Health, University of Rochester FACES: The National Craniofacial Association Fibrous Dysplasia Foundation Greater Tampa Bay Oral Health Coalition Harvard School of Dental Medicine IFAA- International Foundation for Autoimmune & Autoinflammatory Arthritis

Indiana University School of Dentistry International Pemphigus and Pemphigoid Foundation Lupus and Allied Diseases Association Moebius Syndrome Foundation National Foundation for Ectodermal Dysplasias New York University College of Dentistry Nova Southeastern University College of Dental Medicine Rutgers University, School of Dental Medicine University of Minnesota School of Dentistry Sjögren's Syndrome Foundation Stony Brook University School of Dental Medicine Support For People With Öral And Head And Neck Cancer (SPOHNC) Texas A&M College of Dentistry The Ohio State University, College of Dentistry

The Oral Cancer Foundation The TMJ Association, Ltd. UMMC School of Dentistry University of Alabama at Birmingham School of Dentistry University of Connecticut School of Dental Medicine University of Iowa College of Dentistry University of Missouri-Kansas City School of Dentistry University of Texas School of Dentistry at Houston University of the Pacific, Arthur A. Dugoni School of Dentistry University of Utah School of Dentistry Western University of Health Sciences College of Dental Medicine

⁷⁰ Slade, G, Akinkugbe, A, and Sanders, A. Projections of U.S. Edentulism Prevalence Following 5 Decades of Decline. Journal of Dental Research 2014 Oct. https://www.ncbi. nlm.nih.gov/pmc/articles/PMC4212322/

⁷¹ Tooth Decay, NIH Fact Sheets. Research Portfolio Online Reporting Tools. https://report. nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=129

⁷² QuickStats: Prevalence of Untreated Dental Caries in Primary Teeth Among Children Aged 2–8 Years, by Age Group and Race/Hispanic Origin—National Health and Nutrition Examination Survey, 2011–2014. MMWR Morb Mortal Wkly Rep 2017;66:261. DOI: http:// dx.doi.org/10.15585/mmwr.mm6609a5

⁷³ Cuckler, G., Sisko, A., et al. "National health Expenditure Projections, 2017-26: Despite Uncertainty, Fundamentals Primarily Drive Spending Growth," February 2018, Health Affairs: https://doi.org/10.1377/hlthaff.2017.1655

SECTION D: TEMPLATE LETTER TO INFLUENCERS OR DECISION MAKERS

[DATE] The Honorable[Fill in decision maker's name] [Address] [Address]

Dear [Fill in decision maker's name with appropriate title],

[NAME OF ORGANIZATION] calls on <insert name of decision-making body: Congress, Parliament, the Prime Minister, etc.> to prioritize funding for <insert advocacy ask here: increased funding, a specific program, etc.> for <enter time period: fiscal year, project timeline, etc.>.

The health of the mouth and surrounding craniofacial structures is central to a person's overall health and well-being. Providing support will improve the lives and health of *<insert appropriate geographical area*>.

Left untreated, oral diseases and poor oral conditions make it difficult to eat, drink, swallow, communicate and maintain proper nutrition. Scientists also have discovered important linkages between gum disease and heart disease, stroke, diabetes, and pancreatic cancer.

Investments in oral health research is critical to stay ahead of evolving trends. Tooth decay, gum disease, oral cancers and craniofacial congenital anomalies, such as cleft lip and palate, impose heavy health and economic burdens. Cutting-edge research allows *<insert appropriate geographical area>* to be a leader in prevention efforts. Below are examples of important research:

<List examples of research your institution is conducting. Include the public health impact>

<List examples of research your institution is conducting. Include the public health impact>

<List examples of research your institution is conducting. Include the public health impact>

<Include if relevant: For your consideration, below is a table delineating specific programmatic funding requests. With constrained budgets, [ORGANIZATION NAME] understands the difficult task of allocating funding, and we greatly appreciate your consideration.>

<Add concluding paragraph and include contact information>

Sincerely,

<Insert organization name(s)>

Sustained Funding is Critical to Improve and Maintain Oral Health

Oral health is critical to the overall health and well-being of an individual. Investments in oral health research are needed to prevent and control oral and craniofacial diseases, conditions and injuries.

Unmet Needs

<In this section, outline the activities that remain unfunded or underfunded. Be sure to tailor this section to your region's needs; list as many as is appropriate.>

- ▲ Unmet need 1
- ▲ Unmet need 2
- ▲ Unmet need 3

KEY FACTS⁷⁴

- ▲ Worldwide, 60–90% of school children and nearly 100% of adults have dental cavities.
- Dental cavities can be prevented by maintaining a constant low level of fluoride in the oral cavity.
- ▲ Severe periodontal (gum) disease, which may result in tooth loss, is found in 15–20% of middle-aged (35–44 years) adults.
- ▲ Globally, about 30% of people aged 65–74 have no natural teeth.
- Oral disease in children and adults is higher among poor and disadvantaged population groups.
- A Risk factors for oral diseases include an unhealthy diet, tobacco use, harmful alcohol use and poor oral hygiene, and social determinants.

⁷⁴ World Health Organization Oral Health Fact Sheet: http://www.who.int/oral_health/ publications/factsheet/en/

Regional/Local Information

<Explain why oral health is essential to general health and quality of life. Provide local information to support your request for resources (e.g., What is the prevalence and incidence of dental diseases in your region? How many people do not regularly seek oral health care? What are evolving and emerging trends in oral health in your region?).

Keep this section simple; avoid using jargon or technical terms. Remember, your decision makers are not likely scientists, so use terms, messages, and examples that will resonate with a non-scientific audience.>

Public Health Impact

<Describe the public health impact and implications of sustained funding to your region. How would this funding improve the public's health? What would happen if funding was not provided? Are there particular vulnerable populations who would be impacted the hardest?>

Priority Action Areas

<*In this section detail your advocacy "ask". This might include increases to funding for oral health research, support for a specific program or initiative, supporting specific legislation, expanding workforce, building general infrastructure, increased access to oral care, etc.*

Reiterate how funding could help meet these needs if it was available, or share how programs or initiatives are currently working to fill these gaps in care. >

Contact Information

<Include your contact information so decision makers can follow up or request additional information>

CONCLUSION

This toolkit provides a wealth of resources for your next advocacy campaign. Whether you are new to advocacy or a seasoned expert, or whether you read the toolkit cover to cover or skimmed the sections relevant to your needs, remember that advocacy can be fun; learn from your peers and colleagues, relish in new opportunities, and take pride in your wins along the way. Most importantly, remember the ultimate goal your advocacy: to advance funding and policies for research and ultimately, the improvement of lives around the world. Keeping the "big picture" in mind as you navigate the complexities and nuances of advocacy will not only keep the campaign's minor setbacks in perspective, but it will also serve as the motivation to help you reach your goals.

For more information on any of the information contained in this toolkit, please contact the IADR office at research@iadr.org. If you are not already an IADR member, and would like information on how to join the organization, please email us at memberservice@iadr.org.

Want to share your advocacy stories? Email IADR and keep us posted on your advocacy efforts by geography and help us keep this toolkit relevant for years to come.







CONTACT INFORMATION

International Association for Dental Research

1619 Duke Street Alexandria, VA 22314, USA

research@iadr.org +1 703.548.0066