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Toward a Demand-Driven, Collaborative Data Agenda for Adolescent Mental Health

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 A B S T R A C T

Purpose: Existing datasets and research in the field of adolescent mental health do not always meet the needs of practitioners, policymakers, and program implementers, particularly in the context of vulnerable populations. Here, we introduce a collaborative, demand-driven methodology for the development of a strategic adolescent mental health research agenda. Ultimately, this agenda aims to guide future data sharing and collection efforts that meet the most pressing data needs of key stakeholders.

Methods: We conducted a rapid literature search to summarize common themes in adolescent mental health research into a “topic map”. We then hosted two virtual workshops with a range of international experts to discuss the topic map and identify shared priorities for future collaboration and research.

Results: Our topic map identifies 10 major themes in adolescent mental health, organized into system-level, community-level, and individual-level categories. The engagement of cross-sectoral experts resulted in the validation of the mapping exercise, critical insights for refining the topic map, and a collaborative list of priorities for future research.

Discussion: This innovative agile methodology enables a focused deliberation with diverse stakeholders and can serve as the starting point for data generation and collaboration practices, both in the field of adolescent mental health and other topics.

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 IMPLICATIONS AND
 CONTRIBUTION

The present methodology delivers a collaborative, demand-driven, and strategic research agenda that better reflects the needs of key stakeholders in the field of adolescent mental health. Adoption of this methodology can lead to more efficient and impactful data generation and collaborations for the promotion of adolescent mental health worldwide.

Adolescence, here defined as the developmental period between ages 10 and 19 years, is characterized by rapid physical and psychological development and heightened vulnerability to the onset of mental health problems. It is estimated that half of all mental health conditions manifest by early adolescence and

that 10%–20% of all children and adolescents experience at least one mental health condition [1], with higher rates among females and those exposed to poverty, trauma, abuse, and/or violence [2,3]. In countries like the United States, the last two decades have shown a steady rise in the number of adolescents seeking and receiving treatment for anxiety, depression, disordered eating, and suicidal ideation [4]. Adolescent mental health, understood as the absence of diagnosable conditions and a broader state of wellbeing involving self-realization, healthy responses to stress, productivity, and integration in a community

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[5] now faces increased challenges with the novel coronavirus disease 2019 pandemic and its widespread impact on adolescents' daily lives, including prolonged periods of social isolation [6,7].

Improving adolescent mental health worldwide requires access to relevant data that can answer complex research questions and facilitate evidence-based solutions. It is imperative to close the gap between the data that are currently available and the data that are most urgently needed by health policymakers, program implementers, and researchers, particularly in low-income and middle-income settings. For example, an international commission on youth wellbeing co-organized by the World Health Organization, the United Nations Children's Fund (UNICEF), and The Lancet recently found that limited data exist on how to promote mental health on a large scale, a topic that is essential to the work of several youth-focused organizations [8].

Closing this supply-demand data gap is an ambitious task that will likely require decades of arduous, multisectoral research, collaboration, and generous financial support. This article aims to take a necessary first step in this direction: setting a shared, strategic agenda with the main priorities for adolescent mental health research moving forward. Specifically, we introduce a methodology that leverages rapid-research and multisectoral participatory processes to deliver a demand-driven, collaborative, and condensed list of priorities for research that reflects the evidence that stakeholders need to access to solve the most pressing issues in adolescent mental health.

This proposed research agenda can be readily used by researchers, practitioners, and policymakers to inform the strategic allocation of resources for new research projects, indicators for regular monitoring, and the formation of cross-sectoral data-sharing collaborations. In the long term, we expect that the widespread adoption of this methodology by relevant stakeholders will ultimately help us collectively close the supply-demand data mismatch, and most importantly, that it will fuel the creation and implementation of high-impact initiatives that solve the most pressing issues in the field of adolescent mental health.

Methods

The demand-driven methodology for agenda setting presented here was informed by the 100-Question Initiative established by the Governance Laboratory (henceforth the "GovLab"; [Supplementary Information](#)). This initiative is a collaborative cross-sectoral approach to the identification of the most pressing policy questions that could be answered if data and data science techniques were used in a responsible manner [9] and echoes similar collaborative approaches increasingly being deployed to set research and policy agendas around the world [10].

This section describes the three sequential components of our methodology: (1) the development of a rapid-research topic map of current adolescent mental health research; (2) two virtual workshops with several experts to discuss the strengths and limitations of the topic map; and (3) a final topic prioritization based on feedback from the workshop participants.

Development of a topic map via rapid research

We first set out to develop a topic map of current adolescent mental health research. A topic map, developed through The GovLab's Rapid-Search Methodology [11], is a summary of the

major topics in empirical research within a field. Although rapid reviews have certain limitations compared to traditional systematic reviews over longer periods of time, research has shown that they generally result in similar findings [12].

The map organizes topics as per a three-level framework inspired by existing public health frameworks [13]: (1) System-Level, related to organizations, laws, power structures, and technological innovations; (2) Community-Level, related to societal norms, attitudes, and practices; and (3) Individual-Level or Family-Level, related to the practices, behaviors, beliefs, and unique social and biological vulnerabilities of individual adolescents and their families. Each topic was further divided into key subtopics, each including an illustrative, nonexhaustive list of actionable research questions.

To develop the topic map, members of The GovLab along with UNICEF colleagues consulted research partners with expertise in adolescent mental health and conducted a rapid search of publicly available journals, conference programs, reports, and databases in the English language published between the years 2010 and 2020. Topics included are meant to reflect common areas of inquiry driving research and programmatic work on adolescent mental health around the world whose better understanding could inform the development and implementation of high-impact and scalable interventions. In addition to commonality, the criteria used to determine the topics, subtopics, and research questions to include in the topic map were the following:

- 1 **Desirability:** Would investment in the topic have the potential to transform our understanding of adolescent mental health and support impactful interventions?
- 2 **Novelty:** Is the topic ripe for the generation of new insights or the refutation or extension of existing knowledge?
- 3 **Feasibility:** If the requisite resources are made available, could stakeholders make meaningful progress toward improving the topic in the near term?
- 4 **Scalability:** Does the topic exist in varied contexts and therefore lend itself to the scaling and/or replication of effective solutions?

Supplementary Information provides more details on the rapid search and topic map methodology, including the databases and key words consulted for the search and inclusion and exclusion criteria used.

Gathering expert feedback via virtual workshops

The topic map was meant to serve as a starting point to spark discussion on research agenda prioritization among key stakeholders around the world. The GovLab, in consultation with UNICEF, identified professionals and researchers at think tanks, universities, international bodies, businesses, and organizations who have both adolescent mental health knowledge and data science expertise. We invited these experts to join one of two virtual workshops held in June 2020, with the ultimate purpose of helping us create a consensus-based, authoritative research agenda for adolescent mental health with a focus on measurement and monitoring.

A total of 54 experts attended the workshops: 44% of them from multilateral organizations, 30% from academia, 17% from nonprofit organizations, and <1% were government representatives or independent consultants. The vast majority of

participants were based in Europe and the United States, with a handful in Africa, South Asia, and Australia.

During the meetings, the experts were split into breakout rooms of approximately 16 people each, moderated by organizers from The GovLab and UNICEF, to provide their feedback on the accuracy of the topic map, existing gaps, and potential improvements.

Quantitative research agenda prioritization via online survey

We sent a brief postworkshop survey to all attendees to capture their preferences for topic prioritization. Specifically, experts indicated which five topics or subtopics they believed should be prioritized for future investment and focus. Participants completed the survey within a month after the workshops were held. Based on pooled participant responses, a ranking of most to least prioritized topics is presented in the Results section.

Results

Adolescent mental health topic map

Following The GovLab's Rapid-Search Methodology, the main themes in adolescent mental health research were summarized into a topic map composed of 10 topics organized by system-level, community-level, and individual-level categories (Figure 1). This map was finalized in early June 2020 and was the one presented to experts at the virtual workshops; research published since then is not reflected in the map and expert feedback received on the map is presented in the next section ('Virtual Workshops with Experts'). An abbreviated version of this map is presented below.

System-level topics

- (1) *Promoting mental health service access and utilization.* A large portion of adolescents is unable to seek support due to exorbitant costs or a lack of service availability [14,15]. Financial support and innovation in technological tools and management frameworks for patient care might facilitate the prompt detection and treatment of mental health problems in adolescents.
 - *Promoting service use:* How does the removal of barriers to access (e.g., via health insurance or cash transfer programs) influence the utilization of mental health services and medication?
 - *Detection of mental disorders:* How can practitioners leverage developments in magnetic resonance imaging, mobile and wearable technologies, and machine learning to more efficiently and unobtrusively detect and treat mental disorders in children and adolescents?
 - *Prevention of mental disorders:* How can relevant stakeholders promptly and comprehensively assess and manage risks and vulnerabilities associated with mental disorders?
- (2) *Destigmatizing mental health and seeding institutional good practice.* Stigmatization of mental disorders is often related to misconceptions surrounding their cause and treatment and is thought to be an important contributor to the underutilization of mental health services [16,17]. A better understanding of the following subtopics might help mitigate stigmatization and its downstream effects:
 - *Understanding stigma:* What are the main factors (e.g., culture, socioeconomic status, religious context) underlying stigmatization and negative attitudes toward children with mental health issues?
 - *Awareness campaigns:* Do mental health awareness campaigns on social media or other fora have an impact on public perception and subsequent mental health service use among youth?
 - *Institutional inclusion:* What kind of regulations can be adopted to foster understanding, acceptance, and accommodations for children and adolescents with mental disorders in educational institutions and the criminal justice system?

- (3) *Promoting responsible use of digital technology and media.* Child and adolescent development are increasingly intertwined with the internet, social media, and smart devices allowing for continuous connection with peers and exposure to wide-ranging content [18,19]. The association between these tools and adolescent mental health, and how these tools can themselves be used for the responsible collection of data on adolescent mental health, is not yet fully understood.
 - *Technology use:* What is the association between adolescent mental health and digital technology use?
 - *Technology engagement:* How do mental health conditions influence the specific ways in which adolescents engage with digital technology?
 - *Treatment access:* What are the benefits and risks of delivering mental healthcare through technology instead of (or in addition to) face-to-face interaction?

Community-level topics

- (4) *Promoting youth identity, representation, and inclusion.* Adolescence is characterized by identity formation [20] and the restructuring of social relationships [21], including with family members, peers, and those in their ethnic, religious, or tribal groups. Many policymakers and researchers are interested in better understanding and supporting adolescents through these experiences while combating bullying and/or ostracization.
 - *Mental health and inclusion/belonging:* How can adolescents with mental health conditions attain inclusion and positive engagement with public life?
 - *LGBTQIA+:* What are the most effective and safe ways to help adolescents explore different gender identities and/or sexualities and avoid mental health challenges associated with shame or isolation, especially in areas where the policy or cultural environment is hostile to such identities?
 - *Ethnic/tribal background:* What are the mental health challenges common among adolescents from different minority ethnic or tribal groups?
 - *Religion:* How do mental health experiences differ between adolescents from the majority and minority religious groups and how can service providers mitigate challenges?
- (5) *Treating the effects of trauma, abuse, and exposure to violence.* Many adolescents face traumatic events that can result in long-term effects on mental health [22,23]. Understanding these events and their consequences is crucial to treatment and prevention.
 - *Trauma and cognitive development:* What are the short-term and long-term impacts of exposure to trauma and

violence on mental health and cognitive development in adolescents? How do extreme environments (e.g., abuse and neglect) affect brain development?

- *Diverse experiences*: In assessing the impact of trauma, violence, and neglect on cognitive development and mental and physical health and potential interventions, researchers have focused on the special circumstances of those experiencing gender-based and domestic violence, severe or chronic health issues (e.g., HIV/AIDS, cancer, congenital defects), armed conflict-related violence, immigration and displacement (e.g., refugees), and the climate crisis.
- (6) *Responding to the coronavirus disease 2019 and consequences*. As this topic map was being finalized, the coronavirus disease 2019 pandemic was beginning to unfold as a global, unprecedented public health crisis. While limited research had been published at the time, mental health experts were beginning to note the serious impact the pandemic's disruption of daily life would likely have on adolescent mental health [6,7]. While more research has been published on this topic (e.g., [24,25]), our topic map at the time briefly highlighted the need to better understand the pandemic's impact on adolescent mental health in the context of physical wellbeing, economic effects, social isolation, the development of depression and anxiety symptoms, and vulnerable populations.

Individual-level topics

- (7) *Supporting adolescents through physical, emotional, mental, and social changes*. Adolescence is characterized by a widespread change as individuals undergo biological, physical, cognitive, emotional, and social development. While these changes are part of normal development, navigating them might be challenging, especially for those vulnerable to or already experiencing mental health conditions.
- *Physical changes*: What are the perceptions of puberty among adolescents, parents, and healthcare personnel? How do these perceptions influence adolescent body image? How do these perceptions influence the adolescent need for and use of health services?
 - *Behavioral challenges*: What are the biological, family, and society-related factors underlying adolescents' behavioral problems and conduct disorders?
 - *Sexual and reproductive health*: What is the relationship between adolescent sexual health and emotional wellbeing?
 - *Sleep*: How does insufficient, irregular, and/or poor-quality sleep impact adolescent mental health?
 - *Psychiatric conditions*: How can caregivers effectively support adolescents experiencing or likely to experience psychiatric disorders?
- (8) *Alleviating extreme and everyday stress*. In addition to a multidimensional developmental change, adolescents often face new and increased academic, work, and social demands, all of which can lead to heightened experiences of stress and negative affect [26]. Many policymakers and researchers have sought to gain a deeper insight into adolescents' experiences with stress and how to promote stress management skills.

- *Diverse stressors*: How are adolescent stress and mental health impacted by a wide range of potential stressors such as educational demands, family instability, sudden and prolonged financial shocks, youth unemployment, etc.?

- *Stress management*: Which approaches (e.g., family therapy, stress management training) are most effective in reaching and helping adolescents cope with everyday stressors and crisis scenarios?

- *Psychological resilience*: Which individual factors (e.g., mental and physical health, parental treatment) and behaviors are associated with psychological resilience and vulnerability?

- (9) *Promoting healthy lifestyles and countering addiction*. A frequent feature of adolescence is experimentation with drugs, alcohol, and addictive behaviors such as gambling [27]. Researchers and policymakers alike have sought to better understand and mitigate the negative consequences associated with these risky behaviors.

- *Substance abuse*: What are the effects of recreational drug use (e.g., marijuana) on cognitive development and behavior?

- *Drivers of healthy lifestyle and behavior*: How can caregivers encourage adolescents to make healthier lifestyle choices?

- (10) *Responding to suicidal behavior and nonsuicidal self-injury*. Rates of suicidal and self-harming behaviors are higher among adolescents relative to other age groups, and suicide is one of the leading causes of death at this age [28], prompting many researchers to investigate this worrying phenomenon.

- *Suicidal behavior determinants and risk factors*: What personal characteristics, environmental factors, and behaviors are risk factors for suicidal thoughts and actions in adolescence?

- *Demography of nonsuicidal self-injury*: Which youth populations are most at risk of suffering nonsuicidal self-injury?

- *Suicide prevention*: Which interventions undertaken by educators, caregivers, and others are most effective at preventing youth suicide?

- *Treatment and response*: Which approaches are most effective for caring for individuals following suicide attempts or nonsuicidal self-injury?

Virtual workshops with experts

The topic map presented above was shared with the international experts and youth advocates invited to participate in the two virtual workshops held jointly by The GovLab and UNICEF. The 54 workshop attendees discussed the value of the topic map as an agenda-setting tool, raising a few major takeaways.

First, most participants validated the topic map as a useful starting point for the experts to collectively assess the various gaps in understanding and priorities associated with adolescent mental health. A general concern shared by some participants was that the topic map tended to conflate-related but distinct ideas, such as the detection and treatment of specific psychiatric illnesses (e.g., anxiety and depressive disorders) with a broader promotion of mental health, which implies a state of wellbeing beyond the absence of a diagnosable condition or the

treatment of mental health issues, which might imply a cure, with a more general management of these issues. These participants thus urged the organizers to be more explicit regarding the ultimate target sought by the methodology, as this influences the prioritization of topic areas to pursue moving forward.

Regarding the organization of the topic map, several participants noted that the roles of aspects like education, technology, and mental healthcare cut across all three levels of the map (i.e., systems, communities, and individuals) and therefore should be presented as transversal items rather than siloed in one level. For example, an adolescent may receive care for mental health concerns from a hospital and from community counselors or even more informally from friends and family. With respect to education and technology, participants further noted that the topic map should more directly acknowledge their potential role as protective factors supporting adolescent development and/or as facilitators of mental healthcare.

Moreover, participants called for a more granular mention of age and developmental differences within the adolescent period, noting, for example, that some of the issues included in the map (e.g., youth unemployment) tend to be more relevant to older adolescents relative to younger ones. Finally, a few participants thought the topic map was missing some important cross-cutting dimensions such as the increasing influence that peers have in adolescence and more specific topics like nutrition, physical activity, and adolescent pregnancy.

Topic prioritization by experts via online survey

Fifty three of the 54 experts who attended the workshops completed the postworkshop online survey. The results of the

topic prioritization exercise are shown in Figure 2. The largest number of respondents identified the promotion of adolescent mental health as the first priority, followed by treatment services and provision of support.

Discussion

The present article introduces a new methodology leveraging rapid-research and participatory processes to deliver a demand-driven, collaborative set of priorities for future adolescent mental health research with great potential for impact. Arriving at this list of research priorities involved two major components: the development of a topic map based on the scientific literature summarizing major themes in adolescent mental health research and the engagement of dozens of international experts and youth advocates who shared their feedback and research priorities both qualitatively in virtual group discussions and quantitatively via a brief online survey.

Our methodology contributes to the field of adolescent mental health in several ways. In addition to organizing a wide range of promising research directions by thematic area, the topic map uses concrete and actionable research questions to frame each subtopic rather than relying solely on description. This question-based approach, based on The GovLab's 100-Question Initiative [9], makes it easier for interested stakeholders to understand, operationalize, and implement the next steps required to make progress on adolescent mental health topics. In addition, the map's wide scope empowers stakeholders to approach prioritization discussions from a holistic and strategic point of view rather than focusing on siloed issues one at a time. Similarly, bringing together a wide range of adolescent mental health experts for live deliberations not

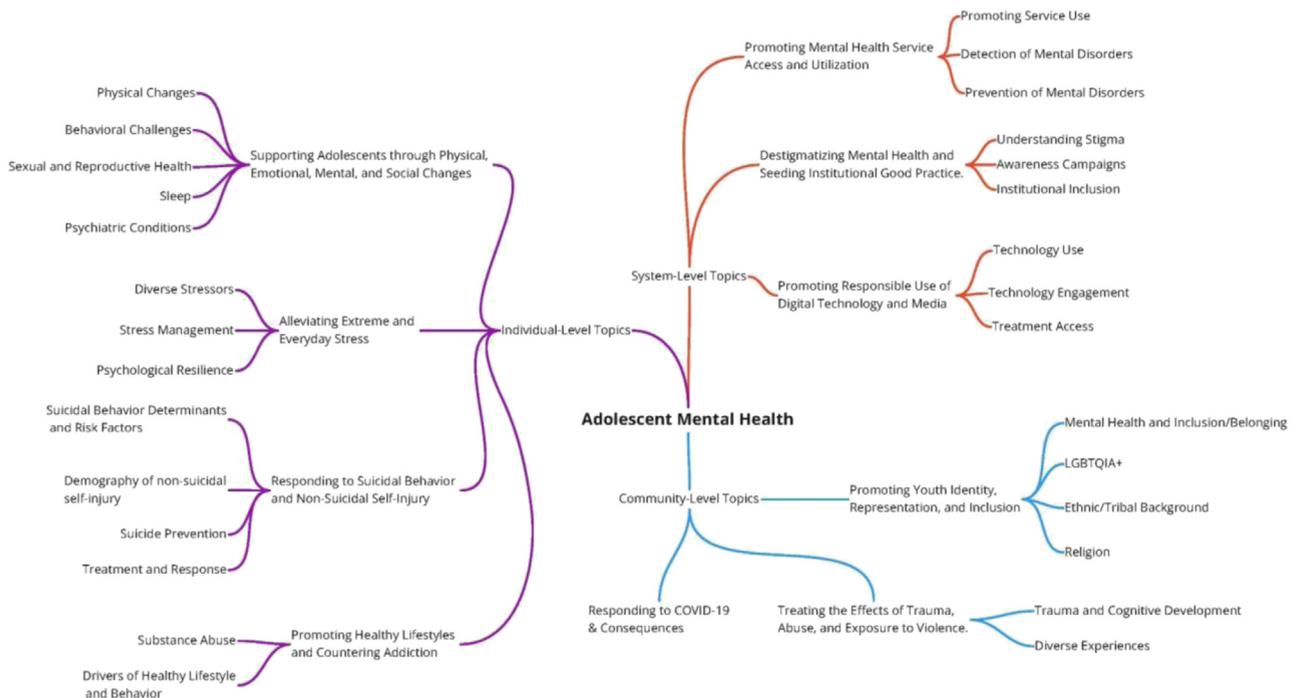


Figure 1. Schematic of the adolescent mental health topic map.

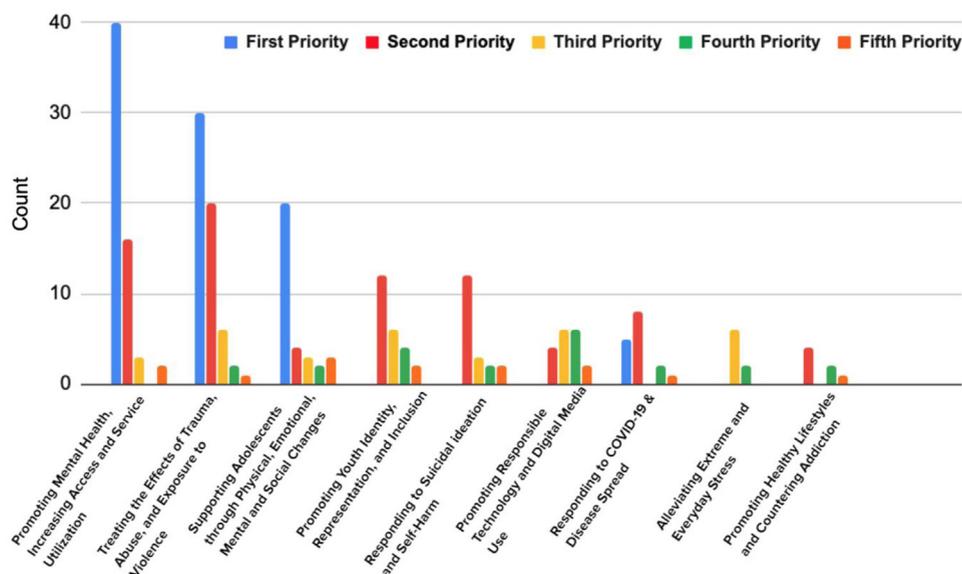


Figure 2. Adolescent mental health experts' topic priorities. Bars indicate the number of survey respondents that identified the respective topic as a priority, broken down by ranking. Bars are arranged left to right from most prioritized to least prioritized.

only helped strengthen the accuracy and legitimacy of our findings but also to identify shared concerns and priorities, thus setting the stage for future cross-sectoral research collaborations.

Of note, the results presented here correspond to the first iteration of our methodology and are meant to serve as a proof of concept illustrating its use, preliminary results, and potential. Limitations of this work should be noted. First, while rapid reviews like the one used to build our topic map generally result in similar findings compared to more comprehensive reviews, they also tend to miss some details. We sought to fill any potential gaps in our topic map via expert consultation at our virtual workshops. However, the group of experts that joined our workshops was relatively small and disproportionately from Europe and North America, which might have biased the feedback we received on the topic map and the results of the topic prioritization exercise. Future iterations are needed to include any voices that might have been left out and to continue to refine the research agenda proposed here. This might include further virtual workshops with greater regional and cross-sectoral representation and the release of updated topic maps integrating this expert feedback. Finally, periodic iterations of this methodology are necessary to ensure that research priorities remain up-to-date with any substantial changes in the adolescent mental health landscape.

Although our collaborative methodology was applied to the topic of adolescent mental health on this occasion, it can be flexibly deployed for other topics that can benefit from similar cross-sectoral and data-driven approaches, from immigration to climate change ("The 100-Question Initiative," 2020). Ultimately, we expect that the continued refinement and widespread adoption of this methodology will give rise to more efficient and impactful data and research collaborations to support adolescent mental health and other important societal issues around the world.

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Supplementary Data

Supplementary data related to this article can be found at <http://doi.org/10.1016/j.jadohealth.2022.05.027>.

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