Guidance on PFAS Testing and Health Outcomes

Board on Environmental Studies and Toxicology
Division on Earth and Life Studies

Board on Population Health and Public Health Practice
Health and Medicine Division
Meeting Goals

• To review the unique purpose of advice from the National Academies

• Share the specific goals and objectives of the National Academies Guidance on PFAS Testing and Health Outcomes

• Discuss the role of community liaisons within this National Academies PFAS study
National Academy of Sciences

“...The Academy shall, whenever called upon by any department of the Government, investigate, examine, experiment, and report upon any subject of science...”

1863 Charter of the National Academy of Sciences
The National Academies of Sciences, Engineering, and Medicine Today

Dual Mission
• Serve as independent scientific advisors to the Nation through our operating arm (7 divisions, 60 boards)
• Honor top scientists (National Academy of Sciences, National Academy of Engineering, National Academy of Medicine)

National Academies are NOT
• Part of the government
• An advocacy organization
• Consultants to for-profit entities
• Research laboratories
• Input from **stakeholders** solicited throughout the study process

• The PFAS Guidance Community Liaison group are stakeholders providing perspectives and insight throughout the process.
Information Gathering vs Committee Deliberation Sessions

- Information gathering (publicly posted and advertised) sessions are required when committee members meet with people other than staff - this includes the study sponsors.
- Any information provided to the committee is also made publicly available.
- Committee deliberation sessions are an important part of the process. These sessions are where committee members discuss ideas, learn from each other, and work towards consensus.

- Special section of the Federal Advisory Committee Act to allow for closed sessions at National Academies Meetings
Information Gathering

• Workshops, other meetings, town halls
• Commissioned work
• Solicitation of input via email or web-based questionnaires
• Material given to the committee by anyone other than Academies staff or their fellow committee members is placed in a public access file
Statement of Task

An ad hoc committee appointed by the National Academies of Sciences, Engineering, and Medicine (NASEM) will consider current evidence regarding human health effects of the most widely studied per- and polyfluoroalkyl substances (PFAS). The National Academies will provide the Centers for Disease Control and Prevention and the Agency for Toxic Substances and Disease Registry (CDC/ATSDR) and the National Institutes of Environmental Health Sciences (NIEHS) an objective and authoritative review of current evidence regarding human health effects of those PFAS being monitored in the CDC’s National Report on Human Exposure to Environmental Chemicals. The National Academies will also provide recommendations regarding potential changes to CDC/ATSDR PFAS clinical guidance including:

• Options and considerations to guide decision-making for PFAS testing in a patient’s blood or urine.
• PFAS concentrations that could inform clinical care of exposed patients.
• Appropriate patient follow-up and care specific to PFAS-associated health endpoints for those patients known or suspected to be exposed to PFAS.
This information will be used to inform how communities and individuals exposed to PFAS could be best served by clinicians. Specifically, the committee will undertake the following tasks:

1. Assess the strength of evidence for the spectrum of putative health effects suggested by human studies (including immune response, lipid metabolism, kidney function, thyroid disease, liver disease, glycemic parameters and diabetes, cancer, and fetal and child development) to establish a basis for prioritized clinical surveillance or monitoring of PFAS health effects. This assessment should characterize the likelihood of those health effects occurring (qualitative probability) given real world human exposures and identify the human populations at most risk (consider life stage, health status, exposure level). Data/evidence gaps that contribute to uncertainty about health effects of most concern should be annotated.

2. Develop general principles for clinical evaluation or biological testing given substantial scientific uncertainty about health effects or the value of such measures in informing care. These principles should address reasons for testing (e.g., opportunities to reduce morbidity and mortality), when to test, who to test, how to test, what to test for, risks of testing, and the related social and ethical implications of testing.
3. Review current knowledge about the contribution of PFAS exposure sources (i.e., drinking water, diet, the indoor environment, etc.) to human exposure and develop principles clinicians can use to advise patients on exposure reduction.

4. Advise whether changes to current CDC/ATSDR clinical guidance/recommendations on PFAS blood or urine testing are needed given the committee’s general principles and assessment of the associations between PFAS exposure and clinically relevant health outcomes. Ultimately, the goal is to provide guidance on how clinicians can advise patients on PFAS testing and health outcomes that may be associated with PFAS as well as what to advise patients regarding standard medical or preventive care and exposure reduction.

5. Outline a process by which the CDC/ATSDR PFAS clinical guidance can be effectively reviewed and revised over the next decade.
What Won’t the Study Do?

• Set a national PFAS drinking water standard
• Propose strategies for regulating PFAS
• Discuss strategies for clean-up, disposal, or removal of PFAS
• Suggest replacement chemicals for PFAS
Project Timeline

Committee Formation
- Announce a call for noms and vet and approve committee members

Information Gathering
- Hold meetings, review literature, commission white papers, and gather other information from stakeholders

Report Preparation
- Determine approach
- Assemble & critique data
- Developing Conclusions
- Study quite phase

Dissemination of report

- September 2020
- May 2022

Town Hall Meetings
- April 7
- May 6
- May 25

Other Informational Meetings
- July 13-15
- August 11 & 12

Report in peer review

Assemble & critique data
Committee Roster

Ned Calonge (chair)
Laura Anderko
Erin M. Bell
Dana Boyd Barr
Kevin C. Elliott
Melissa Gonzales
Erin N. Haynes
Jane Hoppin
Tamarrja James-Todd
Alex Kemper
Brian Linde
Marc-Andre Verner
Veronica M. Vieira
Xiaobin Wang
Chris J. Wiant
Role of Committee Members

• Work with staff to determine the approach to addressing the statement of task
• Assemble the evidence and write the report, with the support of staff
• Discuss and deliberate the reports findings conclusions and recommendations, so that they may come to consensus
• Suggest reviewers of the report
• Address comments from peer reviewers and revise the report
Role of Report Peer Reviewers

- Review the report for accuracy and suggest improvements
- Review report to determine if it met, but did not go outside of the statement of task
- Reviewers do not approve the report, but the review is overseen by a monitor and coordinator that determine whether the committee has adequately responded to the review comments
Role of Staff

• Make sure committee staying within the statement of task
• Keep track of study progress
• Gather information and evidence the committee needs
• Assure the study is complying with rules and processes
  – Example, the committee must sign-off on the report and the report must adequately respond to peer review to be published
Role of Liaisons

• Suggest speakers, topics, and discussion questions for public meetings
• Answer questions to inform the report or the study process
• Provide documents or other data/information to the staff, for committee’s review
• Suggest reviewers of the report
• If you want, help us disseminate the report
• A liaison panel is not a standard part of all National Academies studies
Core Questions for Liaisons

• What potential health effects of PFAS exposure is your community most concerned about and why?
• What is the value to your community of testing individual people for PFAS exposure right now?
• Does the value of getting tested for PFAS exposure depend on how much scientific evidence there is linking exposure to health effects?
• What challenges do you think medical professionals face in providing advice on PFAS exposure?
• For what specific health situations would you like this report to provide advice?
• What routes of exposure to PFAS is your community most concerned about (i.e., drinking water, diet, the indoor environment, etc.)?
Role of Liaisons in Process

Committee Formation
- Announce a call for noms and vet and approve committee members

Information Gathering
- Input into meetings
- Answer questions of interest to the report or the study process
- Provide documents or other information to staff that the committee can review

Hold meetings, review literature, commission white papers, and gather other information from stakeholders

Town Hall Meetings
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Other Informational Meetings
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Report in peer review

Suggest reviewers

Disseminate report

- September 2020
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- Developing Conclusions
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- Determine approach
Final Thoughts

• As liaisons, you will give the committee perspective on the communities their report is impacting

• Thus, they may review the evidence and data with the challenges faced by you and your communities in mind

• We cannot guarantee that you will like the report, but with your help, it will be more likely the committee will have understood your perspectives and needs
Questions

• For more information: https://www.nationalacademies.org/our-work/guidance-on-pfas-testing-and-health-outcomes

• Elizabeth Boyle, Eboyle@nas.edu
Discussion

• Please use the raise hand function or put your questions in the chat
  – At the bottom of your screen, select “Reactions” and then click “Raise Hand”

• We will also call on phone-only participants