

# A Web-Based Tool for Autism Research and the Environment (aWARE)

WORKSHOP REPORT

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This report was developed by Avanti Corporation in collaboration with NIEHS workshop organizers.





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### Introduction and Welcome

The Division of Extramural Research and Training (DERT) and the Division of Translational Toxicology (DTT) at the National Institute of Environmental Health Sciences (NIEHS) have been developing a webbased tool for autism research and the environment (aWARE). The purpose of the <u>aWARE tool</u> is to help understand environmental contributors to autism spectrum disorder (ASD). The NIEHS recently hosted an in-person workshop on September 5-6, 2024 to introduce a test version of the aWARE tool and solicit feedback on its development. Community members and tool developers discussed objectives, scope, and technical aspects of the tool. Attendees also described their own experiences with the tool and provided insights to develop the tool into a valuable resource for the diverse ASD community.

The Director of DERT, <u>David Balshaw Ph.D.</u>, delivered the opening remarks by welcoming attendees to the workshop and reminded them how the core set of values at NIEHS also align with their priorities. He stated that the NIEHS has a long-standing history of community engagement and is also one of the sponsors of the <u>Autism Centers of Excellence</u>. He reminded participants that their feedback would help strengthen the tool and ensure that the tool was responsive to the needs of the community.

The chief of the Genes, Environment, and Health Branch in DERT, <u>Cindy Lawler, Ph.D.</u>, welcomed the participants and stated that the goals of the workshop were to introduce a beta version of the aWARE tool, solicit input from the participants, and use feedback to improve the tool. Currently, there are complex challenges in communication about ASD and the environment. While multiple sources of information are available for various communities, understanding and interpreting research studies is complicated. It is important to know existing literature to understand the context of new research studies. The aWARE tool aspires to address these shortcomings by providing a single source of trusted information, building a glossary of terms, and providing data visualizations and plain language summaries of some of the articles. She charged participants with using the aWARE tool to identify patterns and gaps in research. She also invited them to ponder about the kinds of questions that could be answered by the tool.

## The aWARE Tool

The acting chief of Integrative Health Assessments Branch (IHAB) at DTT, <u>Andrew Rooney, Ph.D.</u>, introduced the methods used in building the aWARE tool. He explained that the IHAB provides literature review and evaluation capabilities for DTT and the National Toxicology Program (NTP). It supports decision making in environmental health research and policy through the development and application of innovative informatic approaches that produce fit-for-purpose assessments. This literature-based evaluation includes using systematic reviews to answer specific questions by evaluating evidence on groups of studies addressing the same or similar endpoint. Systematic evidence mapping (SEM) aims to use data to inform public health decisions by making data more accessible. SEM evaluations categorize and display research relating to relatively broad and complex research areas. The visual presentation of





data coupled with interactive and user driven format aids in greater understanding and evidence-based decision-making. The aWARE tool was developed as a curated catalog of observational and experimental literature which would be updated as new studies are published. It enables users to search, sort, and filter through the studies thus making the data more accessible.

A postdoctoral research fellow at DTT, Anisha Singh, Ph.D., introduced and presented a demo of the aWARE tool. The landing page provides a brief description and list of evidence maps in the tool. It also includes a navigation page which provides a detailed guide on how to use the tool. The 'Highlighted Papers' page offers plain language summary of selected studies and a link to the original study abstract. The tool also includes an Interactive Reference Flow (I-REFF) diagram which summarizes the literature search and screening process.

During the question-and-answer session that followed, Andrew Rooney, Ph.D., clarified that the current version of the aWARE tool contains publications only for the past five years. The demo version was created to gain inputs from participants about the information captured and presented. While the visuals and format won't change drastically, the format would be updated periodically based on feedback received during this and future workshops. The tool would be updated once a year with the possibility of quarterly updates using some artificial intelligence automation approaches.

Participants questioned if the tool would include features to summarize the weight of the evidence. The tool is currently designed to collect, search, sort, and filter information. Moving forward, the tool would ideally strike a balance between bringing the information together, keeping it tied to the uncertainties, and the study quality without making a judgement. The tool developers will consider adding a field for additional input.

After the demonstration, participants were asked to test the tool and provide feedback during breakout room discussions. Some attendees were granted access to the tool before the workshop for testing. These attendees shared their experience of using the tool during the workshop.

A member of the community engagement advisory board at the Duke Autism Center of Excellence, <u>Jeff</u> <u>Day, Ph.D.</u>, searched the tool for literature on a couple of different topics. While he was unable to find any studies that link environmental factors to sleep disorders, he did find several papers that suggest significant correlation between certain pesticides and severity of autism outcomes. He suggested adding a glossary to the tool to facilitate comprehension, a way to save search papers for future reading, and an additional resources page with links.

Chief Science officer at the Autism Science Foundation, <u>Alycia Halladay</u>, <u>Ph.D.</u>, explored how advocacy organizations could use the aWARE tool. A major use of the tool could be to answer different questions from family members about exposures. It could also be a good resource to find research gaps. Funding agencies could also use the tool to determine research or funding priorities.

An assistant professor in Michigan State University Department of Pediatrics and Human Development, Daniel Campbell, Ph.D., identified differences in exposure categories between human and animal

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studies. He also compared human and animal studies based on exposure and study characteristics and found a discrepancy between the number of studies in humans vs animals. For example, air pollution and metal exposures are studied less often in animals than humans and pesticide exposures are studied more often in animals than in humans.

An assistant professor at Johns Hopkins University, <u>Aisha Dickerson, Ph.D.</u>, helped a graduate student generate a dissertation topic. She found that the aWARE tool was easy to use despite the limited search feature and difficulty in removing previous selections. She suggested adding data about medications and adding separate sections for diagnostic and screening tools.

### **Outreach and Communication**

The second day of the workshop included a panel discussion on outreach and communication. This session had three goals:

- Creating interactive visual outreach resources for public engagement with science.
- Best practices for conveying information about the tool to different and relevant communities.
- How to sustain community engagement after the tool's release.

The chief of Child Development and Disability branch at the Centers for Disease Control and Prevention (CDC), <u>Matthew Maenner</u>, Ph.D., discussed the <u>Autism Data Visualization tool</u> developed by the CDC. The tool was developed in response to common questions about autism prevalence as there was a lack of reliable resources for that information. It balances scientific details with readability, runs in the user's browser, and meets accessibility requirements. During development, the developers sought input from subject matter experts, test users, and CDC leadership. They also sought revisions from CDC communications specialists and shared the tool in advance with Autism partner groups. The tool uses four different data sources and developers put out an announcement whenever new data is added to the tool.

The director of research operations at <u>Simons Powering Autism Research for Knowledge</u> (SPARK), <u>Kiely</u> <u>Law, M.D.</u>, discussed the SPARK program launched nationally in 2016 by the <u>Simons foundation</u> to recruit, engage, and retain a large and diverse community of individuals with autism and their families and provide researchers with a clinically and genetically characterized cohort. The program matches families with research studies and provides researchers access to existing data in SPARK. Once the research is complete, the data generated is added back to SPARK and distributed to other researchers. SPARK also generates a lay summary report once research is published. The program values transparency in all communication by stating limitations of research and study timelines. They also ensure that all material is accessible by using plain language and increasing number of materials available in alternative languages such as Spanish. The program has a dedicated helpdesk team that responds to community questions and feedback and a communications team that engages with participants and other community members at conferences and on social media.





The communications director at U.S. Environmental Protection Agency (EPA), <u>Emily Snyder</u>, presented on the Center for Public Health and Environmental Assessment Scientific tools. These tools range from a workspace to support human health assessments to a watershed model to visualize the effects of green infrastructure decisions and support the mission of understanding the complex interrelationship between people. EPA develops brief training videos that include background technical information and demonstrate tools in <u>recorded webinar series</u>. She mentioned the challenges that EPA faced with outreach including having multiple audiences for one tool which made it difficult to develop user friendly interfaces. It was also challenging to accurately convey technical information at a level where people outside of the field of study could understand it.

### Feedback and Suggestions

The two-day workshop included breakout room discussions on both days centered around different themes. Participants were divided into groups with facilitators moderating each group discussion. The first breakout session was focused on participants experiences with using the aWARE tool, user interface and interaction. Specifically, participants were asked the following questions:

- In their initial interaction with the tool, did the participants learn something new or interesting?
- How did the tool facilitate that learning?
- How do they see themselves using the tool going forward?
- What would make them more likely to use the tool?

After the breakout discussions a representative from each group summarized the discussion for the remaining members. These summaries have been broadly categorized here as either feedback for the existing tool and suggestions for improvement.

#### Feedback after using the tool:

- Participants agreed that the tool was helpful, but it lacked sufficient content. Users also found it difficult to navigate from research studies to lay summaries.
- The tool was easy to use but had a limited search feature and popups could be distracting.
- Participants observed that the navigation could be more intuitive, especially for tabs and headings, which could have better labeling and explanations.
- The numbering system and use may impact legibility for users with visual impairments.
- Participants had a hard time resetting the search.
- Mostly US based studies were available and none of the studies were available in additional languages.
- The tool could help highlight gaps in research, showing areas where there are a few studies or unaddressed exposures, thus guiding future research or funding priorities.





- Participants noted that the tool could be useful to families and care givers in a couple of different ways:
  - A useful tool for families encountering new diagnosis to understand where environmental factors could be at play.
  - As individuals across the spectrum age, it would be helpful to help them understand the environmental factors that they are likely to encounter that could impact their autism diagnosis.
- Participants also observed that the tool did not include any information for families on how to mitigate environmental exposures.
- Users noted that the tool was missing clinical and behavioral indicators including some important outcomes such as self-injury behaviors. They did agree that this could be due to lack of data or underreporting in studies.
- Participants remarked that tool could be a valuable way to connect researchers and the public through surveys, studies and other groups, but it lacked a call-to-action button or any way to engage.

#### Suggestions to improve the tool:

- There was a consensus that users would like to have explicit information that was easily available from the website. This included information on how the scope of the included studies was determined and what the whole screening process was. Users suggested that the inclusion criteria should be refined to ensure relevant studies were captured in search results.
- Participants noted that better search features were required including:
  - The ability to carry over searches across tabs.
  - Refine search by categories, for example, human vs animal studies.
  - Being able to search and see search results counts for specific terms.
  - $\circ$   $\;$  The ability to search seamlessly for synonyms.
  - A way to save previous searches or share results with others.
  - $\circ$  The need for subscription alerts tailored to specific searches or interests.
  - Search results hyperlinking to all potentially relevant interesting parts of the database that are available.
- It would be interesting if the tool could keep track of searches being submitted. This would help to keep track of what people are interested in, and what the most common chemicals of interest are for families and the public.
- Participants suggested providing additional information such as:
  - A Q&A page to clarify scope of the tool and methods used in lay terms.
  - A page for glossaries and definitions.
  - A resources page which provides links to other relevant databases.





- It would be beneficial to provide plain language summaries for all studies. The group acknowledged the fact that it compromised best practices, but that it would be beneficial to get the resources out there and then refine them.
- Users also suggested providing best practices for plain language, and including keywords in the summaries.
- Participants expressed concern about using ChatGPT for producing plain language summaries, especially the reading level that ChatGPT produces. Currently, the plain language resources are at an 8<sup>th</sup> grade level. However, participants suggested reducing them to the 4<sup>th</sup> grade level.
- There was a discussion about individual investigators providing their own language resources to reduce the administrative burden and increase accuracy but that would need further development and investigation.
- There was a discussion about plain language summaries vs easy to read summaries stating that those two tools are distinct and separate and would therefore need to be vetted differently.
- It would be helpful to have a rating not only of the individual studies but to have strength of evidence showing association including if the association is positive or negative for a chemical or a group of chemicals. A bottom-line evaluation would really make it easier and more useful for clinicians or families and others.
- There was a suggestion to provide further information in the tool about what a correlation or link means since sometimes that can be misinterpreted as causation.
- The current tool is targeted towards researchers. There was a discussion about creating separate pages for researchers and families or care givers since different user groups (scientific community vs the public) have varying priorities and usability needs. A tab or column on exposure sources will be helpful for families and advocacy groups. Lay summaries and more intuitive tools are necessary for public understanding, while scientists may require detailed search options and quality measures for studies.
- Questions remained about whether a single tool could meet the needs of all potential users.

Breakout discussions on the second day of the workshop were focused on the following specific themes. Meeting organizers also provided some questions as prompts to kick start the discussions.

- Theme 1: Technological wishes and Scientific Data;
  - An overview of PECO and how AI is leveraged for data extraction and tool development.
  - What level of detail is necessary for the data to be useful?
  - Are there features that would facilitate integration of data from this tool with your work processes (e.g., export)?
- Theme 2: Accessibility and Comprehensibility;
  - How intuitive is the user interface?
  - Are there any specific suggestions for making it more user-friendly?
  - Is the plain language summary sufficient and helpful? What improvements would you suggest?



- Are there specific types of visualizations that would better meet your needs?
- Are there any accessibility features that are important to you?
- Theme 3: Visualizing Emerging Trends and State of the Science;
  - What emerging trends in your field are you most interested in tracking?
  - $\circ$   $\;$  What visual would be most useful for your work or interesting to you?
  - $\circ$  How well does the tool identify and visualize these trends and the state of science?
  - How easy was it to interpret the trends and present state of science using the current tool?

At the end of the breakout discussions, representatives from each group presented a summary of their discussions to the remaining members.

**Technological wishes and Scientific data** – this group discussed evidence map workflow and opportunities for automation and refinement. Participants made the following suggestions:

- The literature selection process does not make any judgements about the quality of different studies. Special considerations are needed for neutrality of NIEHS, EPA, and other agencies in reporting.
- Participants discussed if low quality studies should be included to provide a comprehensive overview of existing evidence and if those studies should be marked for quality.
- They also discussed the issue about different conclusions coming from different reviewers of the papers and how to include information about quality (example for evaluation sample size, appropriate study design) especially if humans are making inclusion decisions.
- Participants asked for transparency on why some papers were excluded and how to follow up on disagreements about exclusion.
- The process still requires manual oversight and cannot yet be fully automated for selection of papers for inclusion.
- Detailed systematic literature reviews with humans require enormous efforts. Participants wondered if AI could be used in reviews with rapid updates and new publications and provide tools for lay people to extract use from literature.
- Questions were raised about the use of data in policy making and how NIEHS is involved in determining hazards of substance versus decisions about risk.
- Participants cautioned that the tool may be harmful to someone without a background in science since incorrect conclusions may be drawn from evidence. Neutral presentation of data can lead to issues with possible misuse. They suggested that there should be a way to determine whether the majority of studies are inconclusive and specify that they cannot determine causality.
- There was a discussion about who in the Autism community had reached out about the need for the tool. Workshop members heard from caretakers and parents, but wondered how the tool was helpful to someone with ASD. They pointed out that listening sessions and workshops





would help determine how the tool could be valuable for the ASD community, as well as researchers.

- It might be useful to add information on pharmaceuticals but that would cause a very large expansion in the number of papers for screening purposes.
- The main goal should be identifying relevant papers, rather than providing too many details. There needs to be a balance between the first tiers of selection versus fine-grained presentation of multiple details.

Accessibility and comprehensibility – the group discussed the functionality and usability of the tool and ways to ensure that it is accessible for a broad audience. The discussion provided positive feedback as well as suggestions for improvement:

- Positive feedback:
  - The tool was found to be very simplistic and straightforward to use. However, some members did not find it intuitive and were overwhelmed by the navigation section. They also noted that the pop ups didn't always go away.
  - Participants found the columns and colors useful but observed that the numbered tabs did not correlate to user understanding. They also remarked that the "Refresh" button was not easy to find and the "Select/hide" additional filters were not easy to use.
  - Participants appreciated the name of the tool but thought that the childlike nature of the sun logo did not represent Autistic adults.
  - Authors listed in reference search with dates helped make elimination of choices more relevant.
- They suggested the following areas for growth:
  - Adding a glossary and/or a thesaurus features.
  - Having the ability to hide columns or rows and reduce visual clutter while focusing on specific search criteria.
  - Ability to see what top searches were and what other individuals commonly searched for in the tool.
  - Lay summaries with a high level of detail.
  - A universal way to provide access to the full publications without a paywall.
  - Disclaimer that AI is used for plain language summaries, and a way to indicate that they have/ have not been reviewed by a human.
  - Improving language accessibility since tool is currently only available in English.
  - Participants warned that even the paid version of the software "Tableau" had bloated information at the top and the bottom that could navigate a user away from the true tool and vetted information.

**Visualizing emerging trends and state of the science** – the group discussed dashboards and interface of the tool and opportunities for data visualization to inform data analysis.





- The group made the following observations and suggestions:
  - The number one thing that came up in the discussion was that the tool didn't show results. While the public would see a number of studies, those studies may not show associations. The group was concerned that the number of studies could be misleading, and a disclaimer may not be sufficient to counteract the notion that more studies mean evidence of a link.
  - They also noted that there was no information about sample size and suggested that it could be shown in the results.
  - The tool was missing data about important modification factors such as pharmaceuticals, susceptibility factors such as stress and resiliency factors.
  - It also does not capture mechanistic studies, sources of exposures, non-chemical but environmentally scoped exposures such as climate change, green spaces, or noise.
  - The tool should include factsheet pages on exposure sources.
  - More detail was required on the exposure methods. The "other" category needs to be drilled down and categorized more.
  - Participants suggested capturing intersection between nonchemical stressors and environmental exposure (co-exposure):
    - Separating out things that may not be normally included as environmental exposure and categorized as other exposure types.
    - Table/Matrix of all the categories and number of studies, but existing tool categories are not mutually exclusive (one chemical can fall into multiple buckets).
    - Utilizing an "AND" search to find studies that cover more than one chemical.
  - Members suggested including information about what the studies say, not just if there were studies or not and how many studies.
  - Members also suggested including information about findings (positive or negative effects) or adding a statement to the tool saying that it was a tool of studies that exists but does not necessarily mean there was a link.
  - Participants observed that the tool showed the available research but could also be used to identify research gaps to inform funding priorities and research initiatives.
- This discussion group also made the following suggestions for data visualizations:
  - Tracking things overtime:
    - A way to see how many publications on a certain topic over time (trendline of publications) with details on age of exposure, and diagnostic tools.
    - Trends of number of publications per topic- graphs of specific chemicals related to broader topic (example: air pollution).
    - How to get at substitution, some way to convey that within flame retardants for example there are replacement chemicals (put related data in trendline).





- Comparing humans to animals.
- Trends in diagnostic tools use over time.
- Pull out emerging concerns/topics (ex. information on wildfires under air pollution).
- Time trend for anything members were interested in (for example human vs. animal data), not just exposure.
- NIEHS can have preset visuals, but if it could be built to have more user driven visuals that could be created to answer specific questions.
- Show trends in funding initiatives.
- Mapping studies geographically:
  - Either by study population or where the study was published where the study was published was important because diagnostic definitions/tools may be different.
  - Showing where the study population is but making clear to people that that isn't necessarily where people are most highly exposed to chemicals – need clear communication so people know what they are looking at.
  - Mapping study population locations works best for epidemiological data.
  - Mapping where the study was published works best for animal data.
  - Filter the map by study years or exposure types.
- Visuals by study design:
  - Each study design type visual has publication year on x-axis and dots scaled by study size and color-coded by geography, effects on y-axis (positive or negative).
- Extracted Information:
  - When using tool, wanted the extracted information (measuring outcome and exposure), the way it's designed right now is about the counts.
  - For epidemiological studies capturing the age (generation) of the population to know where they stood compared to the national average
  - Is sample size extracted?
  - Modification factors- filter studies for genetics (yes/no), stress, SES disadvantage, nutrition (lumped or specific), pharmaceuticals, geography, urban vs. rural.
- o Identifying what emerging trends in autism and the environment were:
  - Mixtures.
  - Modification/susceptibility.
  - Stress.
  - Socioeconomic status.
  - Nutrition.
  - Heat exposure/climate change.





- Mechanistic studies.
- Built environment/greenspace.
- Plastics.

#### **Closing remarks**

The chief of the Genes, Environment, and Health Branch in DERT, <u>Cindy Lawler, Ph.D.</u>, delivered the closing remarks. She thanked attendees for their participation, feedback, and the richness of the suggestions and discussions. She stated that the NIEHS tool developers would need time to digest all the suggestions. She also reminded participants that it wasn't realistic to convene people in person regularly so NIEHS would be considering ways to organize smaller virtual sessions.

<u>Andrew Rooney, Ph.D.</u>, stated that the richness of the feedback was fantastic and moving forward the NIEHS would have feedback that would make the tool more impactful. He also admitted that creating data visualizations would be more challenging and it would take a lot more time and thought to identify ways to capture the language and the understanding and the caution with which the information would be presented.