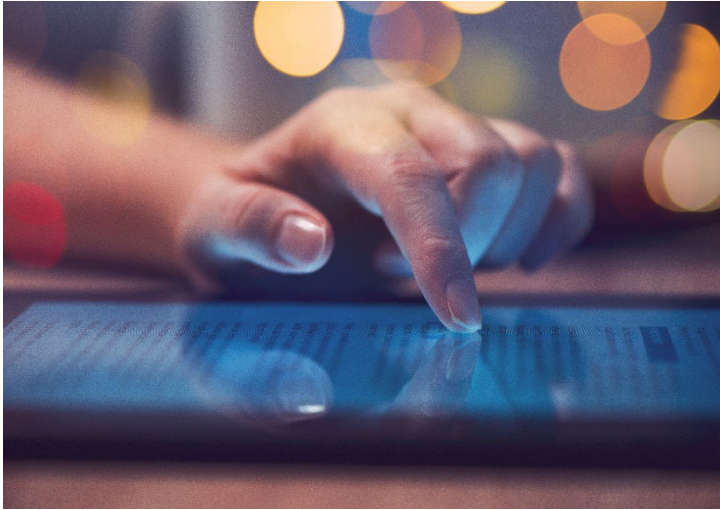


# Understanding Autism Research

Information regarding autism research and care strategies is widely available across various platforms, including online resources, print media, books, and podcasts. To ensure the reliability of information, it's best practice to assess its **source**. This document outlines strategies for identifying high-quality autism information, provides sources for finding original research, explains the components of a peer-reviewed article, and explains how to know if a study is relevant to you.



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## How to spot good information

The following questions will help you determine whether information concerning autism biology and care is reliable.

### Does it center autistic voices?

Centering autistic voices through participatory autism research is crucial because it ensures studies address the true needs and priorities of autistic people, shifting focus from "cures" to improving quality of life and promoting acceptance. This inherently enhances research quality by integrating invaluable lived experiences, leading to more valid and effective interventions. Ultimately, including autistic perspectives upholds the right to self-determination and builds trust, fostering ethical and truly beneficial research for the autistic community.

Learn more about the importance of participatory research and investigations led by people with autism in Dr. Wenn Lawson's presentation, *Autism Research: Nothing About Me Without Me* at <https://autism.org/autism-research-nothing-about-me-without-me/>

## What is the source of this information?

Blog posts, books, pamphlets, social media posts, websites, news stories, or other non-journal sources can bring information to your attention, but it's up to you to check their sources. Is the information based on studies and research, or is it the opinion of the author?

The most credible source of information is peer-reviewed journal articles because they are reviewed by several experts who suggest revisions or reject the article. Information found in popular media (e.g., Time Magazine, Wall Street Journal, New York Post, Fox News, New York Times, People Magazine) is reviewed by an editor for typos or grammar, but it does not undergo the rigorous expert review that peer-reviewed articles do.

Therefore, there is no way of knowing whether it is true.

It is essential to approach information on blog posts, social media posts, and websites with skepticism. Some questions you might want to ask yourself when reading information include:

1. Does the author provide any citations to back up their claims, or are they all anecdotal (such as before-and-after pictures of a person who lost weight with a specific diet, which may or may not be real)?
2. If the authors do provide citations to back up their claim, what are the sources of those citations?
3. If the author claims their treatment has resulted in progress, can it be measured? (e.g., objective and measurable: "his language improved from 0 words per day to 5 words per day" versus subjective: "his language seems better")
4. Do the authors report any "baseline" or "pre-treatment" data? If not, it would be like showing the "after" picture without showing the "before" picture.
5. Is the author selling anything? If so, be very skeptical of this information.

## Who performed this research?

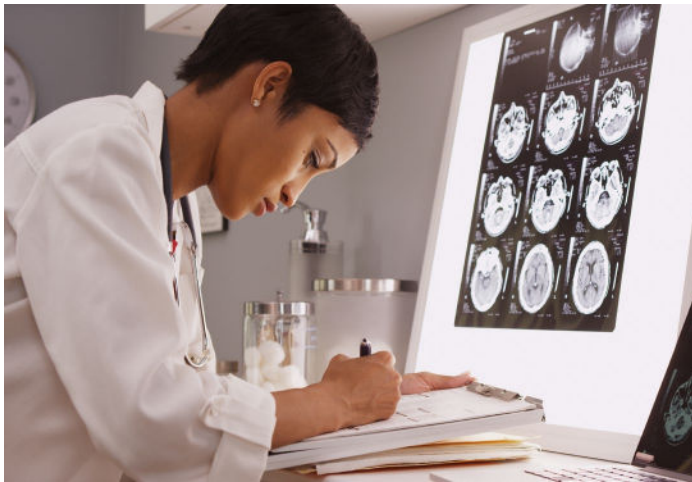
What people, groups, universities, or businesses were involved in this study? Do they have a track record of producing reliable autism research? Be cautious if the author has a vested interest in the outcome of the study, especially if they stand to profit from this research, treatment, product, or service. See if the author is selling anything or if they claim to have a treatment or service that provides a "cure" for autism. If so, you should view the information cautiously.

## Who funded this research?

Does the researcher or institution have any conflicts of interest I should know about? What businesses, funding sources, products, or services might benefit from this study's results?

## What other works are cited in the study?

Are the researchers basing their work on good science? Have they cited earlier studies published in peer-reviewed journals?



### Has the research been peer-reviewed?

Does it appear in a peer-reviewed journal? What is the impact factor of that journal? While a journal may appear reputable, many pay-to-publish journals offer minimal or no peer review. These are often referred to as “predatory journals.” In contrast, articles published in journals indexed in databases such as PubMed.com, Medline, PsychINFO, PsycARTICLES, Web of Science, Ovid, ERIC, or Wiley Interscience are generally considered to be of higher quality due to more rigorous editorial and peer-review standards.

### Has it been replicated?

Have other scientists used the same method to achieve the same results? If not, why not? Can this progress be replicated by anyone else, or can only this one person, clinic, or team of researchers achieve good results (e.g., “our program is so special that only we can get good results?”) Be cautious about accepting any claim that other researchers or studies have not tested and replicated.

## What is a peer-reviewed study?

Peer-review is a process that academic journals use to understand if the studies they publish are based on good research. Before including a study in their publication, the journal sends the research out to other experts in the field. The most credible source of information is from peer-reviewed journals articles. That is because these articles must undergo a rigorous evaluation process by several experts (“peers”) in the same field before being accepted for publication; this helps to ensure the quality of the research.

In peer-reviewed journal articles, experts (“reviewers”) not involved in the original study check that the study design applies scientific principles and procedures. They also use their knowledge of the subject to determine whether the procedures are methodologically sound and whether the results and conclusions make sense based on available data. The journal editor considers the reviewers’ recommendations when deciding whether to publish the study.

Some scientific journals have been in print longer than others or are more respected. Readers can use an impact factor metric to decide if the journal that printed a particular study is a reliable source of information. The Impact Factor is the total number of times articles from that journal were cited, divided by the total number of citable articles in that journal.

The impact factors of various journals are calculated and printed yearly in Journal Citation Reports. You can find the current impact factor of most journals with a quick web search. Remember that a journal must exist for at least two years before its impact factor can be calculated.

## Types of studies

You may encounter several different types of studies as you read and learn about autism. Each study type can be used to investigate autism-related topics, but some have a wider application than others. Knowing the different study types supports critical thinking about how the research applies to you or your child with autism.

**Animal and Cell Studies** - Observe and test animals or cell cultures. These studies often provide initial insight, but the application to humans may not be clear.

**Case Reports** - A written record on a single subject. Each case study represents an individual experience. This can be a starting point for research. It does not prove that what worked for one individual will work for others.

**Case Series** - A group of case reports that track multiple participants. Remember that correlation is not causation. That means that two things can happen simultaneously, but that doesn't prove one caused the other.

**Case-Control Studies** - Examine the experiences of the participant groups—typically, one group consists of individuals with autism and the other without autism (allistic). The investigation is retrospective, meaning it looks at experiences in the past and attempts to draw conclusions. Causation is complex to prove with this type of study.

**Clinical Trials** - Test new medical treatments, interventions, or devices on human volunteers. They are carefully designed, often prospective (looking forward in time), and aim to establish cause-and-effect relationships between an intervention and an outcome. Clinical trials are the gold standard for proving the efficacy and safety of new medical approaches.

**Cohort Studies** -Track the groups receiving the intervention and those who do not. Participants in the intervention group may receive the treatment at varying levels, while those in the control group often receive a placebo. Control participants may be related to those in the treatment group (e.g., siblings) or unrelated individuals.

**Randomized Controlled Trials** - Randomized clinical trials (RCTs) are the gold standard for providing evidence to support the efficacy and safety of new medical approaches. RCTs randomly assign participants to either the **experimental group** (the group that receives the intervention being assessed) or a **control group** (the group that does not receive the intervention; they may receive no intervention, treatment as usual, a “placebo” intervention, or even another active intervention). It is essential to randomly assign participants to groups because it helps ensure that each participant has an equal chance of being assigned to either group,

minimizing the potential for selection bias. This prevents researchers from unintentionally favoring certain groups or individuals.

Randomization also makes it more likely that “confounding variables” (factors that may influence the outcome but are not the focus of the study, such as participants in one group being in poorer health than participants in the other) are evenly distributed across groups. This means that outcome differences between groups are more likely to be caused by the treatment rather than other



confounding factors. Before randomization, participants are often matched on one or more variables—such as sex, age, or communication level—to ensure comparability between groups. The test group receives the treatment while the control group receives a placebo (this can be a placebo pill, as in a study of a medication treatment, or a psychological placebo that controls for attention from a therapist [e.g., supportive therapy], as in a study of a behavioral or psychotherapy treatment). This type of study can be blinded or “masked” (study participants don’t know which group they’re in) or double-blind (the researchers who are assessing the outcome also don’t know which group the participants are in).

**Single-Subject Experimental Designs** - Single-Subject Experimental Designs (SSEDs) are research methods that focus on how interventions affect an individual case rather than groups. These designs involve repeated measurements of a behavior over time, comparing baseline performance to performance during intervention phases. Researchers use SSEDs to establish a causal link by observing consistent changes in an individual’s behavior when an intervention is introduced or removed. They are particularly useful for in-depth understanding of individual change and for situations where large group studies aren’t feasible.

**Systematic Review** - Compares and contrasts the results of several randomized controlled trials and draws conclusions based on the quality of the studies and their results.

## Where to find sources

Many groups, organizations, and individuals write about autism. You can check the validity by seeking sources whenever you come across new information, whether biomedical research or otherwise. You can often find original research publications/sources in

- [PubMed](#)
- [ERIC](#)
- University websites
- Journal websites

- Medline
- PsychINFO
- PsycARTICLES
- Web of Science
- Ovid
- Wiley Interscience

Websites that end in .edu or .org may be more likely to contain credible information than websites that end in .org and .com — and .org may be more likely to be credible than .com — because .edu domains are associated with universities and .org domains are often associated with non-profit organizations, whereas .com domains are typically used for commercial businesses and websites. However, actual credibility of a website depends on many factors besides its domain extension, such as the author's credibility and expertise, whether the information provided is supported by evidence (e.g., data from peer-reviewed journals), the site's affiliations and potential biases, the presence of proper citations or references, whether the website is regularly updated, etc.

Some of these research aggregation services are free, while others cost money. Check with your local library for paid services to see if they can connect you with a free account. You can also ask your clinician to provide you with research related to specific treatments, comorbidities, and symptoms. Good research studies generally ask questions and address them through replicable scientific investigation. Be sure to note any conflicts of interest and ensure the methods are sound.

## Anatomy of peer-reviewed research publications

Peer-reviewed articles follow a specific publication layout that ensures comprehensive study descriptions. This includes investigative contexts, reasoning, hypotheses, findings, implications, and limitations. Articles are broken down into the following sections:

### Abstract

The abstract is a succinct summary of an entire work that highlights a study's purpose, methods, results, and conclusions. By reading the abstract, you can determine whether the article is relevant to yourself, your family, your work, or your research. Remember that abstracts present the study from the author's perspective, who, just like everyone else, is functioning under a particular set of biases. If an article's abstract seems to align with your topic or aim, you can read the introduction or background section for more information on context and potential implications.

### Introduction/Background

The introduction sets the stage for the rest of the article. This is where researchers share the study questions and hypotheses and provide historical context for the importance of their questions. Science is an iterative

process, and it is essential to understand the significance of research within the context of our evolving understanding. By reading the introduction, you can gain an understanding of the research problem, its relevance, and the specific questions the study aims to answer. This section helps to contextualize the research within the broader scientific landscape and provides the necessary background to appreciate the study's contribution.

## Methods/Methodologies/Frameworks

This section details how the study was conducted, comprehensively describing the research design, participants (if applicable), materials, procedures, and data analysis techniques. It should be sufficiently detailed for another researcher to replicate the study. By carefully reading the methods section, you can gauge whether the participant demographics will represent your personal experience and assess the rigor and validity of the research. This section is crucial for evaluating whether the study's design and execution address the research questions appropriately and identifying potential limitations or biases in the methodology/framework.

## Results/Findings

The results section presents the objective findings of the study clearly and concisely, typically using text, tables, and figures. It describes what the data shows without interpretation or discussion of implications. The results section describes the observed study outcomes. From the results section, you can observe the raw data, trends, and statistical analyses that emerged from the study. This provides an opportunity for personal evaluation of the evidence based on one's experiences. This is good practice before reading the discussion section, where the author explains their thoughts and assessments.

### *Statistical Significance*

In most research studies, a statistically significant finding indicates that the observed differences between two groups are not due to random chance alone. This means there's a high probability that a real effect or relationship exists. The results section of an article can often seem dense or overwhelming, but by looking for indicators of statistical significance, you can efficiently identify the key findings and highlights of the research.

## Discussion

The authors interpret their findings about the research questions and existing literature in the discussion section. They explain the results, discuss their implications, and consider study limitations. This section often refers to the introduction to contextualize the study findings within the greater discourse. The discussion usually includes comparing the current findings to previous research, exploring potential mechanisms or explanations, and suggesting future investigations. By reading the discussion, you can gain insight into the authors' interpretation of their work, its broader significance, and how it contributes to the growing body of knowledge. In other words, the discussion section answers, "so what?"

## Conclusion

The conclusion concisely summarizes the main findings and their most important implications. It often reiterates the study's key message and may suggest future directions for research or practical applications. While sometimes integrated into the discussion, a separate conclusion section offers a final, impactful statement. The conclusion lets a reader quickly grasp the study's core takeaways and overall contribution to the field.

## How to tell if the research applies to you



Consider the "Who, What, Where, When, Why, and How" of the research to determine if it may apply to your lived experiences or research interests:

**Who** were the participants/participants? Are the people or participants in the study like you or the group you're interested in? For example, a survey of children is not relevant if you're interested in adult health.

**What** was the topic of study? Is the specific intervention, behavior, or phenomenon being studied directly related to your interest?

**Where** was the study conducted? Was it in a lab, a clinic, a community setting? Does the environment of the study impact its generalizability to your life?

**When** was the study published? While foundational research can remain relevant, newer research often supersedes older findings, especially in rapidly evolving fields like medicine or technology.

**Why** was the study done? Understanding the underlying goals of the research can help you gauge its utility for your own purposes.

**How** was the study conducted? While you don't need to be an expert, a basic understanding of the methods can help you assess the credibility and applicability of the findings. Was the study design strong enough to support the conclusions?

## Opportunities to participate in research

Researchers recognize that their work, no matter how meticulously designed, relies entirely on the participation of people in the autism community. Every advancement in understanding and every intervention developed or refined is contingent upon the willingness of individuals to contribute their time and experiences. In applied research, studies depend directly on the involvement of those with an autism diagnosis.

The decision to participate is always voluntary and often deeply personal. For many, it's fueled by a desire to advance our understanding and the potential benefits of the intervention being tested. Before participating in a study, be sure to weigh the risks and benefits of participating and how it will impact your day-to-day life. It's also critical to ensure confidentiality and that you maintain the right to withdraw yourself (and your information) from the study at any time. If the risks, benefits, confidentiality, and right to data retraction are not all provided, it is best not to participate in that study.

ARI maintains a list of studies with open enrollment for those looking for opportunities to participate in research. Visit [autism.org/opportunities-to-participate-in-research/](https://autism.org/opportunities-to-participate-in-research/) to learn more.