

# European Medical Students' Association

Association Européenne des Étudiants en Médecine emsa-europe.eu | Rue Guimard 15, 1040 Brussels | info@emsa-europe.eu

This policy was adopted by the 8th EMSA Spring Assembly in Lisbon on 8th of May of 2022. Must be reconsidered until: 8th of May of 2026.

# Transparency in Medical Research

Authors: Dilge Kocabaş, Violetta Frantzeska Papadimitriou, Thalia Weigel, Aastha Saurabh

The European Medical Students' Association (EMSA) represents medical students across Europe. We envision a healthy and solidary Europe in which medical students actively promote health. EMSA empowers medical students to advocate health in all policies, excellence in medical research, interprofessional healthcare education, and the protection of human rights across Europe.



## Problem statement

Research is the gateway to acquiring new knowledge and learning more about the world we live in. Transparency in medical research enables the recommendation of the safest and most efficient vaccines, pharmaceuticals, and medical devices based on the best available evidence. However, misinformation can undermine the progress of humanity. Instinctively, misinformation is frequently associated with the media, as media misinformation tends to be more extensive, directly affecting the public. Scientific concepts are often perceived as dull and difficult to comprehend. So, when disseminated as general information they are oversimplified and exaggerated for the sake of interest. In addition, the rise of social media has made it easier for misinformation to spread since source credibility is not always determinable. Paradoxically, misinformation. Therefore, despite the opportunities provided by social media for productive communication and the exchange of information, misinformation flourishes in this setting.

On the other hand, the scientific community faces similar problems - from hype and hyperbole to publication bias and citation misdirection, predatory publishing, and filter bubbles. Like journalists, scientists rely on the attention their work gets. That can lead to the need to hype their work and selectively publish those findings that are surprising and "clickable". The internet has also changed the way research works. A few decades ago scientists relied on hard copies of scientific journals to find sources. Nowadays search engines and research databases are the resources that provide instant access to scientific papers with titles with more interesting framing receiving higher Altmetric scores. Combined with the fact that top-tier journals mostly want exciting results, researchers are encouraged to hype their work, sometimes to the point of fraud. Additionally, researchers may often have conflicts of interest that similarly, consciously or unconsciously, encourage the presentation of research results in a biassed fashion (Dunn et al., 2016).

These circumstances contribute to different types of bias that pose a further barrier to transparency in medical research, with the potential of harming patients, research, and public health. Publication bias and spin belong to the most prominent and well-documented forms of bias within medical research, which require critical attention (Bradley et al., 2020, Albarqouni et al., 2017).

Publication bias denotes the phenomenon of research deemed interesting and novel being preferentially published by scientific journals (Bradley et al., 2020). At the same time, researchers scarcely submit such research for review, further driving the formation of this bias (Bradley et al., 2020). Additionally, Spin encompasses the practice of interpreting and presenting data in a biassed way that garners public attention in favour of the researcher's specific interests (Boutron and Ravaud, 2018). Though falling short of data fabrication or falsification, authors may selectively misreport results, methods or "spin" the discussion in a way that influences the reader's understanding of the study (Boutron and Ravaud, 2018). Ultimately, the dissemination of this misrepresented research bears implications for its subsequent impact on influencing the patient's therapy choices and clinical practice. Following this, we should emphasise the crucial role of transparency in medical research not



only for practitioners, but also for patients. Access to first-hand data establishes trust and inspires the confidence and comfort needed by patients to undergo therapeutic procedures. In this way, transparency empowers patients by providing them with the opportunity to educate themselves on their diagnosis and therapy choices.

While mentioning transparency in medical research, open access which refers to the information that is publicly available and accessible over the internet without any cost, can't be left aside. Clinical trial registration on publicly accessible databases, access to patient data for further analysis, and publishing of results, regardless of the trial outcome, is needed in means of providing transparency in medical research. Moreover, patient-level data should be accessible to permit reanalysis, secondary analysis, group analysis, as well as patient-level meta-analysis. We should highlight the crucial role of research on the framework of treatment practices with access to data from laboratory and clinical trials essential for developing sound hypotheses. The availability of accurate results from various trials and their methods of the experiment also allows scope for evaluation by other researchers and aids the formulation of a structured study. Expanding the clinical question is only possible based on clear results, which in turn creates an opportunity for the advancement of the present data. Even though it is often requested that researchers provide their unfiltered findings and associated methods rather than merely publishing the result, this is not always fulfilled. Only providing a restricted amount of information on the study method, as well as little or no access to the data results in disruption of evidence-based public health decisions. Additionally, it results in indirect expenses not just for the public but also for the patients, who paid for poor or dangerous treatments. As a result, requiring openness would enhance the benefit of the research, while reducing the threats to patients, clinical trial volunteers, and the general public.

#### Our view. Aim

The European Medical Students' Association (EMSA) recognizes the importance of scientific research, which constitutes a cornerstone of medical education and practice. After all, the publication of research is an aspirational goal accompanying medical students throughout their studies and into their future careers. Representing medical students across Europe, EMSA highlights the necessity of reliable, gualified, and authentic sources that are used for medical studies, further medical research, and the development of therapeutic procedures. Since media misinformation, biases, and insufficient accessibility to medical data not just hinder transparency, but also contribute to "research waste" (Chalmers and Glasziou, 2009) and can have a detrimental impact on the allocation of resources, clinical practice, and policy decisions (Turner et al., 2008). To protect the interest of patient welfare as well as future research EMSA will raise awareness for these barriers in front of transparency in medical research and take appropriate measures to combat both the prevalence and impact of intransparent practices in medical research. Lastly, open access is one of the most substantial concepts related to transparency in medical research that medical students can get either a great benefit or harm. With the help of the stakeholders, by raising awareness of this issue and promoting it, we can accelerate the advancements in science! Even if EMSA has already tried to promote transparency in medical research through activities, workshops, and policy papers from different components of transparency such as open access, a policy paper related to transparency in medical



research for structured and accurate advocation is needed. We should underline the fact that the members of EMSA today are researchers and clinicians of tomorrow. Therefore, EMSA promotes transparency while sharing scientific knowledge to advance science itself as well as public health.

#### **Recommendations**

EMSA calls on EMSA members, researchers and scientists to:

- Critically analyse research data and publish the results accurately regardless of the trial outcome
- Register all related informations of clinical trials including the results on publicly accessible databases
- Recognize transparency as a scientific as well as moral responsibility of the research community
- Require transparency and accordingly condem lack of transparency in research
- Use and develop statistical tools to detect reporting biases including spin
- Raise awareness for issues including reporting bias, non-disclosure of conflicts of interest and media misinformation within the scientific community
- Facilitate open access related to their own work as well as promote the same for the researchers and scientists that they can reach out within the scientific community
- Promote and actively engage in accurate science communication

EMSA calls on its FMOs and other student organizations to :

- Promote their members to actively engage in accurate science communication
- Raise awareness for issues including reporting bias, non-disclosure of conflicts of interest and media misinformation within the scientific community
- Require transparency and accordingly condem lack of transparency in research
- Facilitate open access related to their own work as well as promote the same for any individual or organization they can reach out within the scientific community
- Encourage their members to register all related informations of their research including the results on publicly accessible databases

EMSA calls on European Media to:

- Select credible sources and not publish if credibility is not determinable
- Hire experts on science communication
- Not promote fake news and misinformation regarding medical research
- Raise awareness for issues including reporting bias, non-disclosure of conflicts of interest and media misinformation within the scientific community

EMSA calls on Research journals to:

- Provide a publication infrastructure that supports pre-registered studies
- Actively promote pre-registration of studies, making it a benchmark for publication
- Require the disclosure and the detailed description of researchers' conflicts of interest



- Adopt clear policies for dealing with conflicts of interest
- Promote and facilitate open access within their own policies as well as the researchers and scientists that they can reach out

EMSA calls on Pharmaceutical Industry, European institutions, European Healthcare agencies and Universities to:

- Raise awareness for issues including reporting bias, non-disclosure of conflicts of interest and media misinformation
- Promote and facilitate the rigorous documentation of researches on publicly accessible databases
- Facilitate open access within their own policies and encourage the same for any individual or organization they can reach out within the scientific community
- Require transparency and accordingly condem lack of transparency in research

EMSA calls on WHO to:

- Raise awareness for issues including reporting bias, non-disclosure of conflicts of interest and media misinformation
- Promote and facilitate open access within their own policies as well as the researchers and scientists that they can reach out
- Continue to endorse selected primary registries for registration of clinical studies
- Promote and facilitate the rigorous documentation of publicly-funded research on WHO database



## **References**

- 1. Albarqouni, L. N., López-López, J. A., & Higgins, J. P. T. (2017). Indirect evidence of reporting biases was found in a survey of medical research studies. *Journal of Clinical Epidemiology*, *83*, 57-64. <u>https://doi.org/10.1016/j.jclinepi.2016.11.013</u>
- Boutron, I., & Ravaud, P. (2018). Misrepresentation and distortion of research in biomedical literature. *Proceedings of the National Academy of Sciences*, 115(11), 2613-2619. <u>https://doi.org/10.1073/pnas.1710755115</u>
- Bradley, S. H., DeVito, N. J., Lloyd, K. E., Richards, G. C., Rombey, T., Wayant, C., & Gill, P. J. (2020). Reducing bias and improving transparency in medical research: A critical overview of the problems, progress and suggested next steps. *Journal of the Royal Society of Medicine*, *113*(11), 433-443. <u>https://doi.org/10.1177/0141076820956799</u>
- Chalmers, I., & Glasziou, P. (2009). Avoidable waste in the production and reporting of research evidence. *Lancet (London, England)*, 374(9683), 86-89. <u>https://doi.org/10.1016/S0140-6736(09)60329-9</u>
- Lazarus, C., Haneef, R., Ravaud, P., & Boutron, I. (2015). Classification and prevalence of spin in abstracts of non-randomized studies evaluating an intervention. *BMC Medical Research Methodology*, 15, 85. <u>https://doi.org/10.1186/s12874-015-0079-x</u>
- 6. Phillips, D. P., Kanter, E. J., Bednarczyk, B., & Tastad, P. L. (1991). Importance of the lay press in the transmission of medical knowledge to the scientific community. *The New England Journal of Medicine*, 325(16), 1180-1183. <u>https://doi.org/10.1056/NEJM199110173251620</u>
- 7. Turner, E. H., Matthews, A. M., Linardatos, E., Tell, R. A., & Rosenthal, R. (2008). Selective publication of antidepressant trials and its influence on apparent efficacy. *The New England Journal of Medicine*, 358(3), 252-260. <u>https://doi.org/10.1056/NEJMsa065779</u>
- Yavchitz, A., Boutron, I., Bafeta, A., Marroun, I., Charles, P., Mantz, J., & Ravaud, P. (2012). Misrepresentation of Randomized Controlled Trials in Press Releases and News Coverage: A Cohort Study. *PLOS Medicine*, 9(9), e1001308. <u>https://doi.org/10.1371/journal.pmed.1001308</u>
- 9. West, J. D., & Bergstrom, C. T. (2021). Misinformation in and about science. *Proceedings of the National Academy of Sciences of the United States of America*, *118*(15), e1912444117. https://doi.org/10.1073/pnas.1912444117
- Wang, Y., McKee, M., Torbica, A., & Stuckler, D. (2019). Systematic Literature Review on the Spread of Health-related Misinformation on Social Media. Social science & medicine (1982), 240, 112552. <u>https://doi.org/10.1016/j.socscimed.2019.112552</u>

11. Elman, C., & Kapiszewski, D. (2014). Data Access and Research Transparency in the Qualitative EMSA. HEALTH.EUROPE.TOGETHER.



Tradition. PS: Political Science & Politics, 47(1), 43-47. https://doi.org/10.1017/S1049096513001777

12. WHO (2015). WHO calls for increased transparency in medical research. Retrieved February 20, 2022, from

https://www.who.int/news/item/14-04-2015-who-calls-for-increased-transparency-in-medical -research#:~:text=The%20move%20aims%20to%20ensure,by%20the%20best%20available%20evide nce.

- 13. ECRIN (2015). Transparency in Clinical Research. Retrieved February 20, 2022, from <a href="https://ecrin.org/node/583">https://ecrin.org/node/583</a>
- 14. WHO (2022). International Clinical Trials Registry Platform (ICTRP). Retrieved February 20, 2022, from <a href="https://www.who.int/clinical-trials-registry-platform">https://www.who.int/clinical-trials-registry-platform</a>
- 15. WHO (2015). WHO Statement on Public Disclosure of Clinical Trial Results.Retrieved February 20, 2022,from <a href="https://www.who.int/ictrp/results/WHO\_Statement\_results\_reporting\_clinical\_trials.pdf">https://www.who.int/ictrp/results/WHO\_Statement\_results\_reporting\_clinical\_trials.pdf</a>