

Session 5: Opportunities & Challenges for Reporting Findings From Clinical Cancer Research Back to Participants.

Research Perspective

Jeff Yorio, MD

Texas Oncology – Central Austin

Site Research Leader for Central & South Texas for Sarah Cannon Research Institute at Texas Oncology

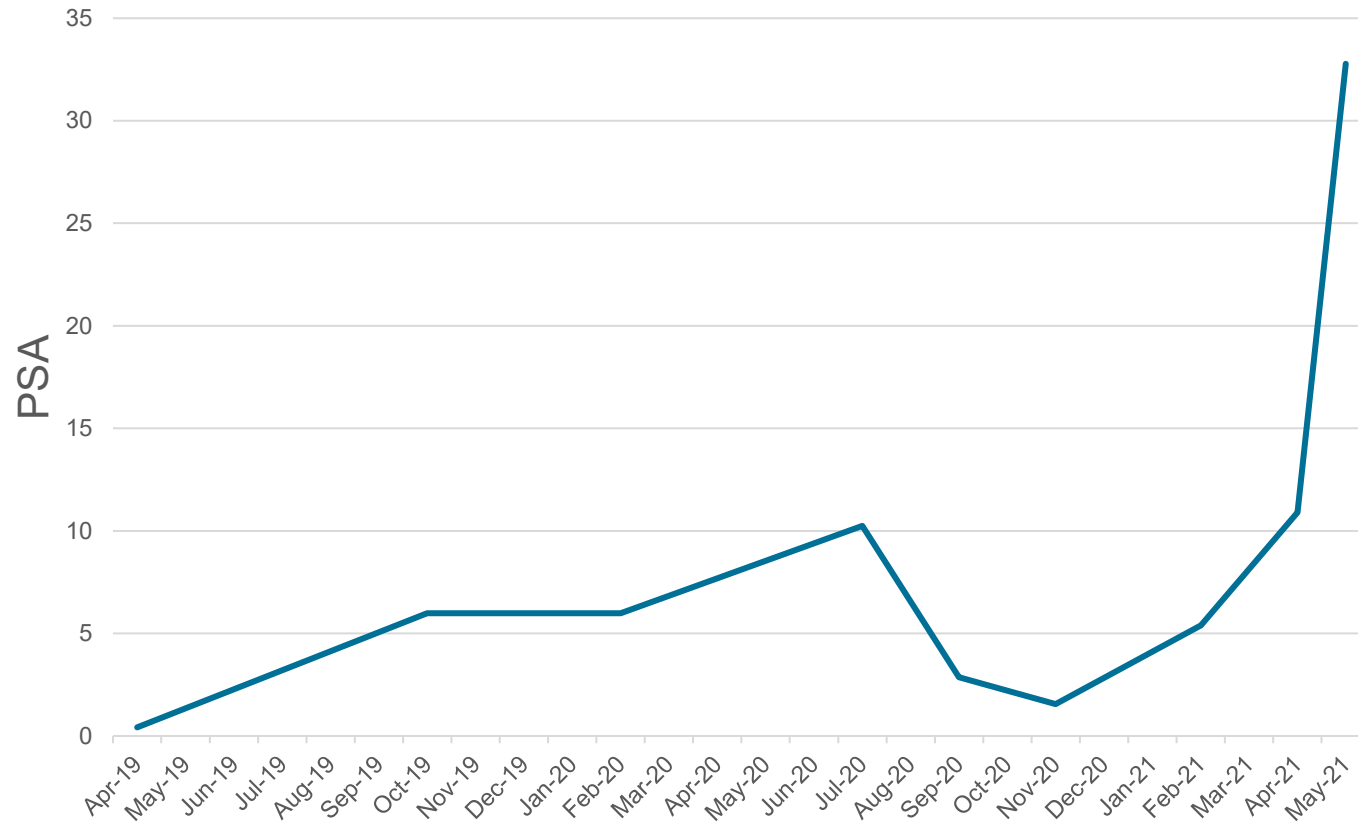
09.30.2025

Disclosures

- Ideology, Castle Biosciences, Replimune, Merck

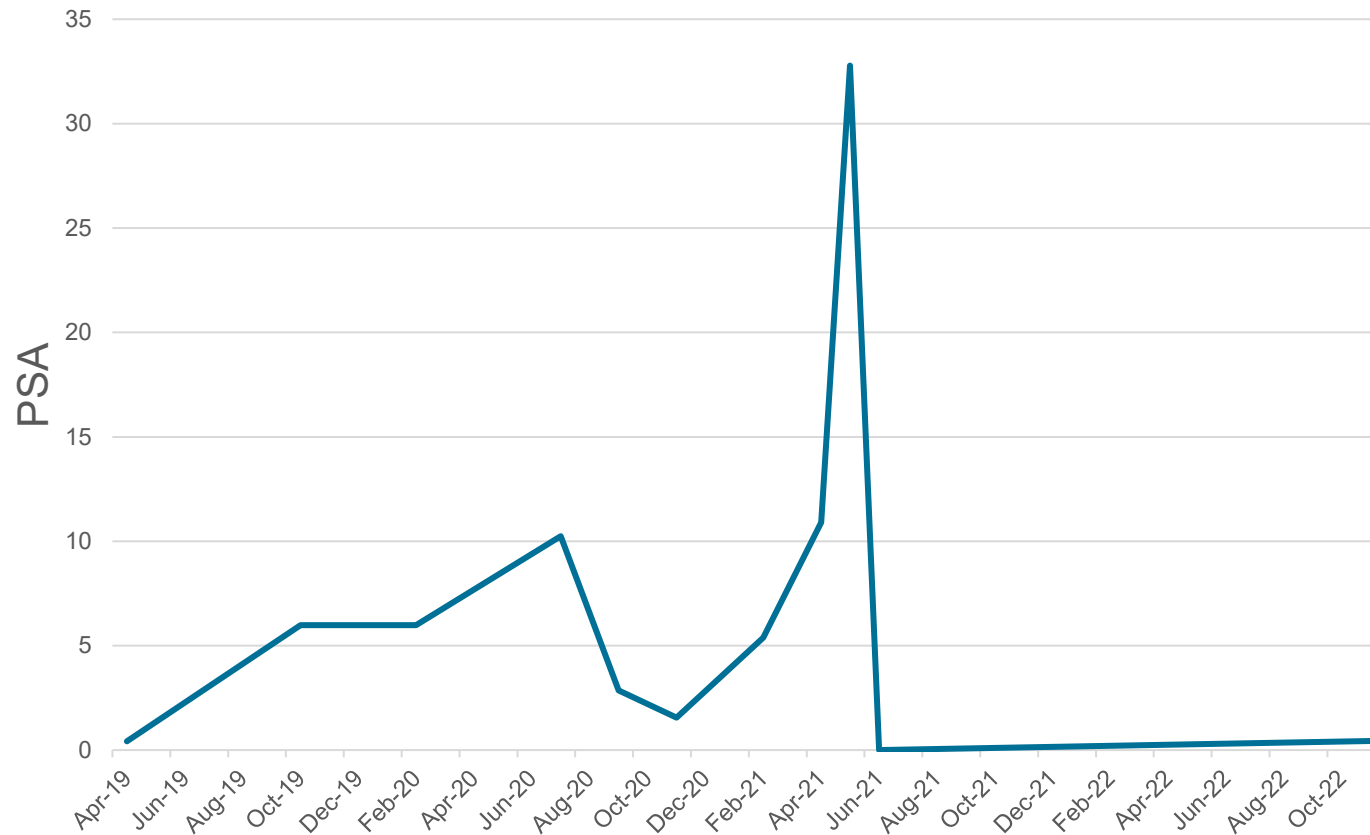
Case

- 63 year-old male with metastatic hormone resistant prostate cancer previously treated with leuprolide, abiraterone/prednisone, enzalutamide, docetaxel, and cabazitaxel.



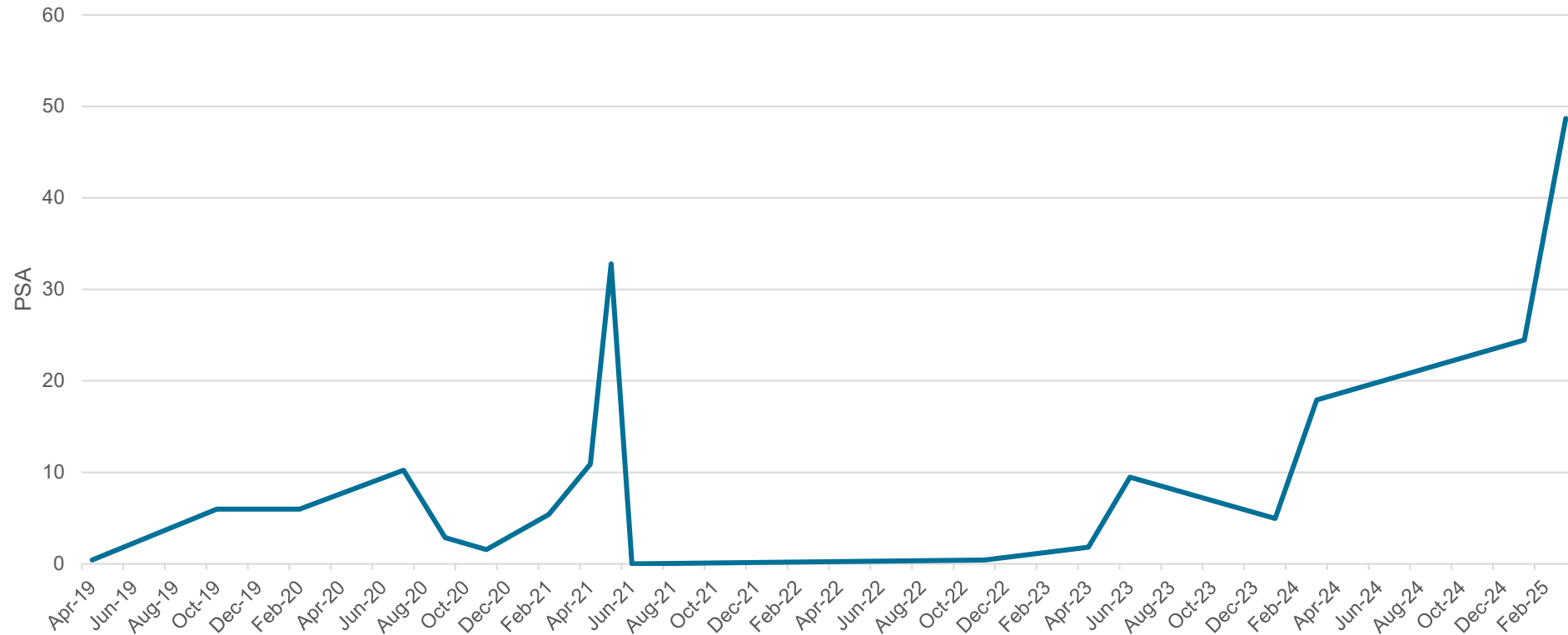
Case

- 63 year-old male with metastatic hormone resistant prostate cancer previously treated with leuprolide, abiraterone/prednisone, enzalutamide, docetaxel, and cabazitaxel.
- Enrolls on clinical trial with dual checkpoint inhibitor immunotherapies.



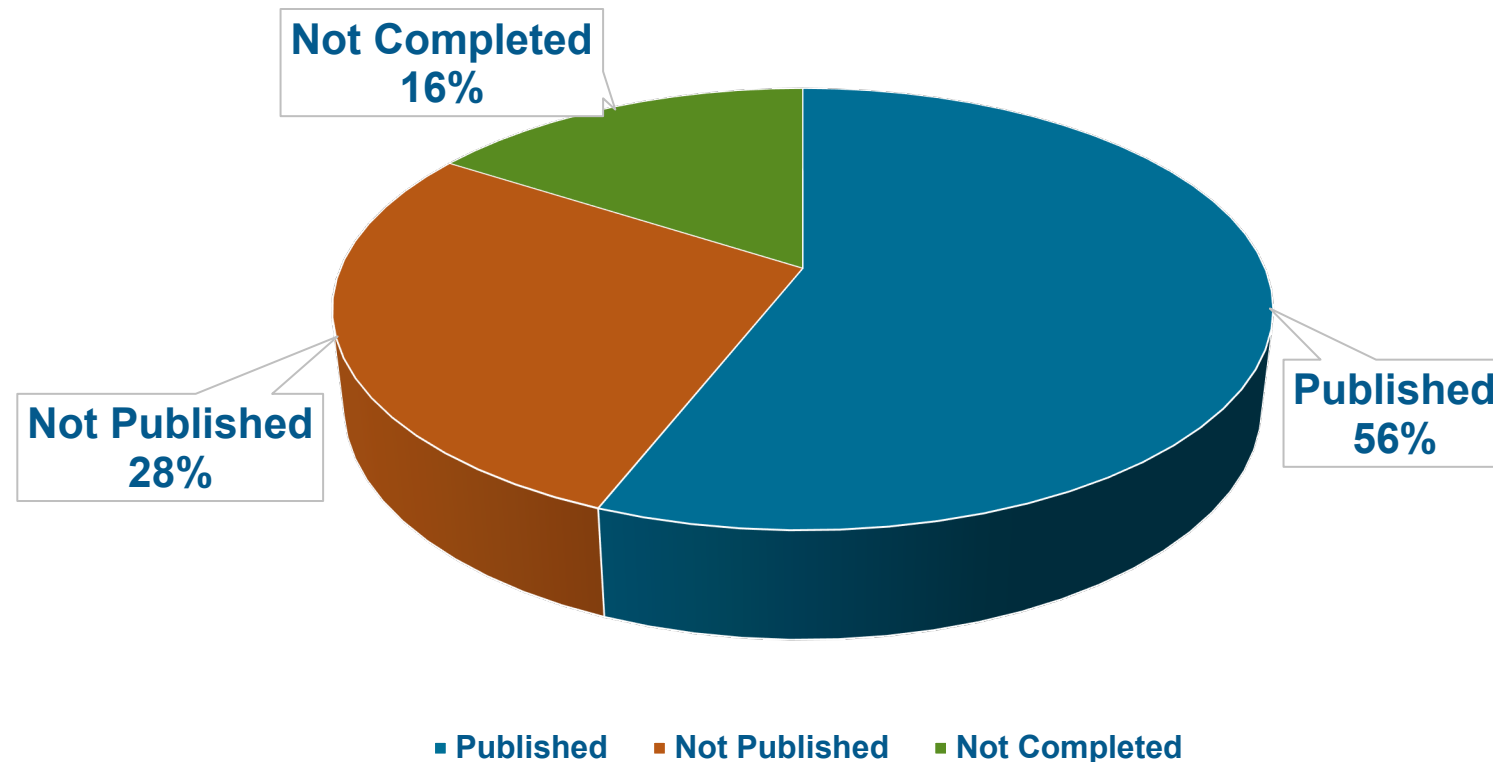
Case

- 63 year-old male with metastatic hormone resistant prostate cancer previously treated with leuprolide, abiraterone/prednisone, enzalutamide, docetaxel, and cabazitaxel.
- Enrolls on clinical trial with dual checkpoint inhibitor immunotherapies.



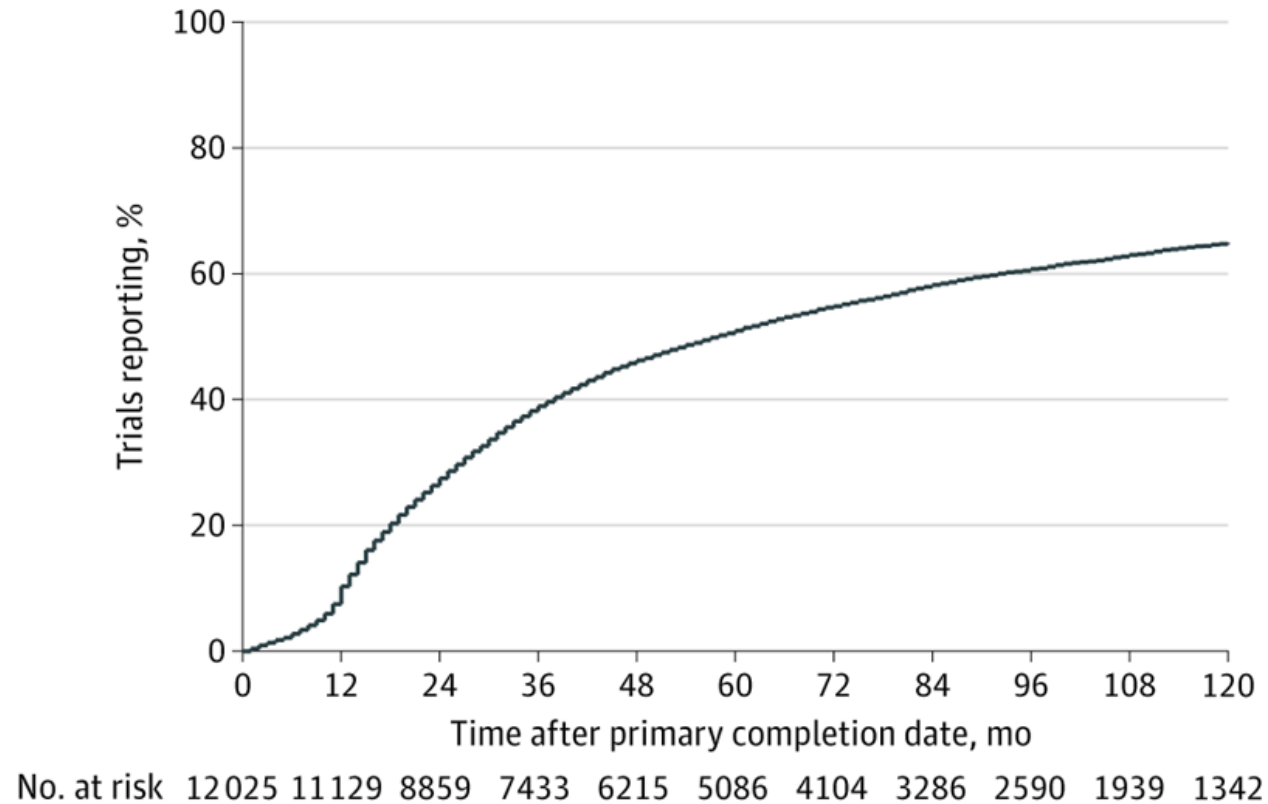
What happens to clinical trial information?

- Publication rate of registered clinical trials in lung cancer. (*Ghassan Al-shbool et al*)
- Identified registered phase II & III lung cancer trials from 1/1/2000 to 8/7/2016.



What happens to clinical trial information?

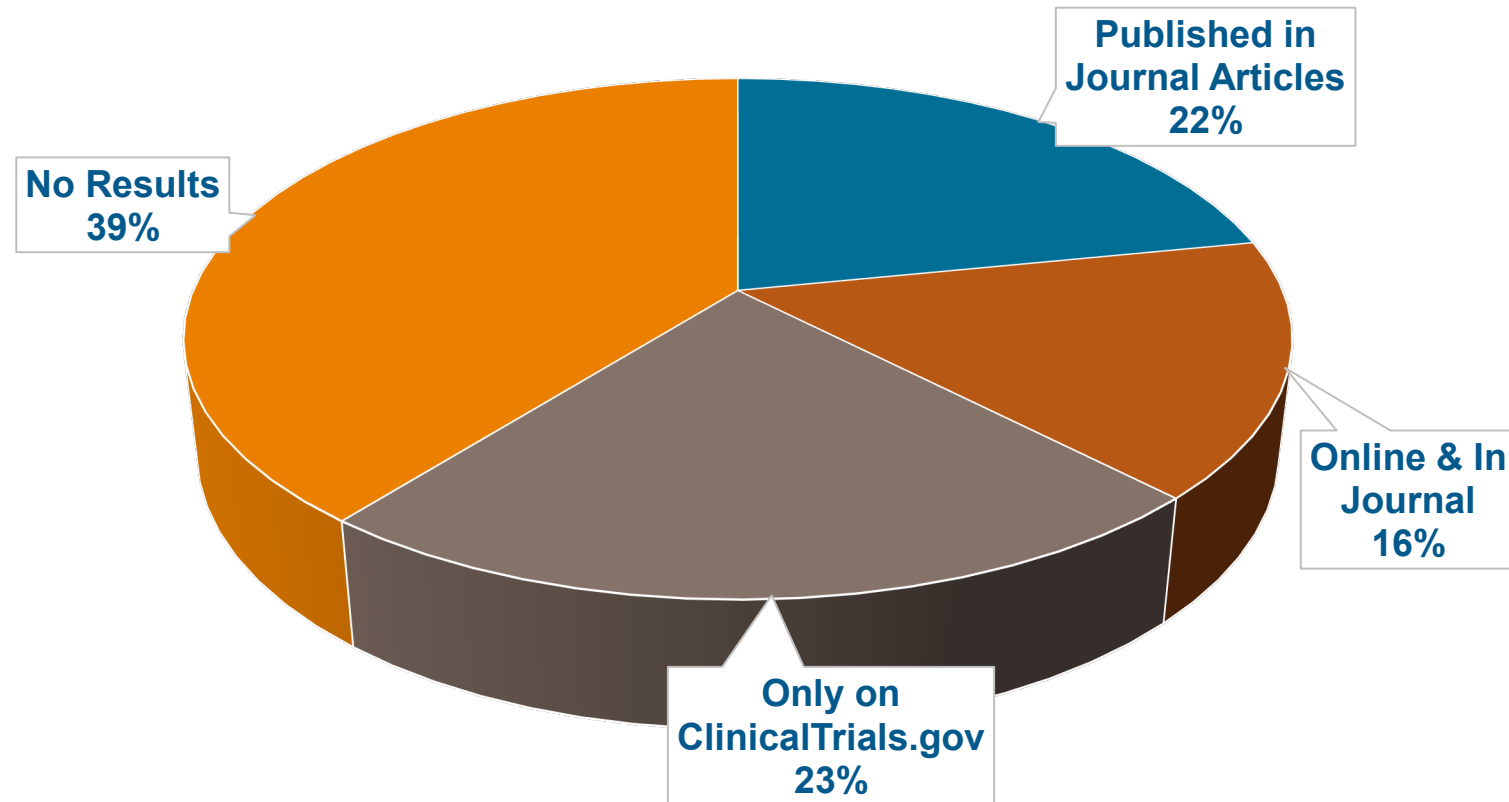
- Reviewed 12,240 completed or terminated oncology trials registered with ClinicalTrials.gov from 2007 to 2017.



Liu X et al. JAMA Netw Open. 2021.

What happens to clinical trial information?

- Reviewed 12,240 completed or terminated oncology trials registered with ClinicalTrials.gov from 2007 to 2017.



Why aren't clinical trials reported?

- Early Terminations
- Single-center trials < Multicenter trials
- Industry-sponsored trials < NIH or academic institutions trials
- Phase I trials < Phase 2 or 3
- Negative studies < Positive studies

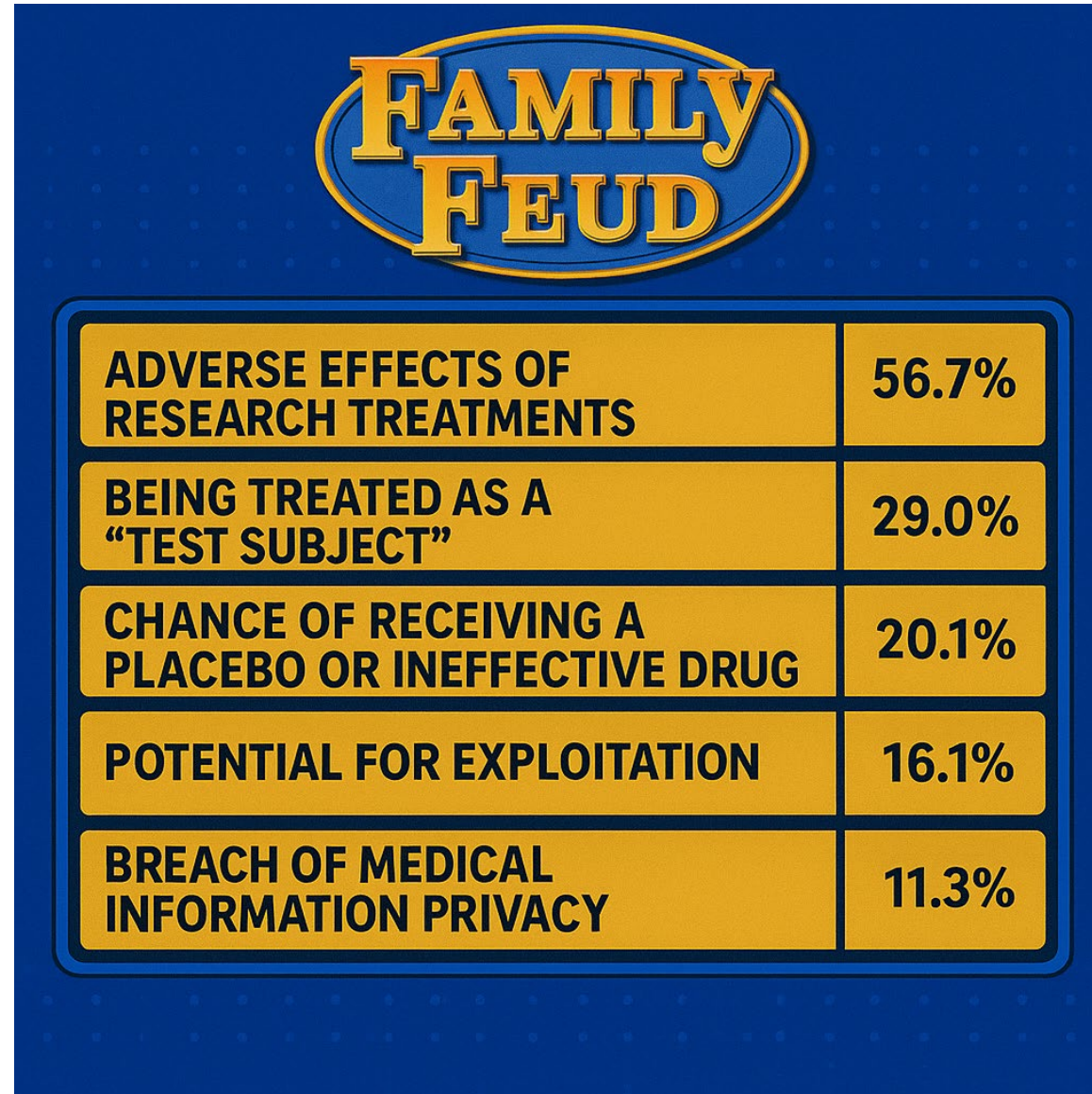
Top 5 Motivations for Clinical Trial Participation



IMPROVEMENT OF ILLNESS	61.8%
ACCESS TO NEW AND EFFECTIVE TREATMENTS	53.4%
DISCOVERY OF GENETIC DISEASES IN THE FAMILY	29.8%
RECEIVING MEDICATIONS FREE	26.1%
RECEIVING MORE ATTENTIVE CARE AND SPENDING MORE TIME WITH HEALTH CARE PROFESSIONALS	25.2%

Tolunay et al. JAMA Network Open. 2025.

Top 5 Concerns for Clinical Trial Participation



Tolunay et al. JAMA Network Open. 2025.

Patient Clinical Trial Journey



Barriers to Reporting Information to Patients

- Long-term follow-up and contact with patients is challenging
- Difficult for physicians & research staff to keep up on long-term results
- For patients with advanced disease, they already know if they responded or didn't respond to treatment so may care less about outcome of study
- Patients with terminal illness no longer alive when information is reported
 - Do we let families know? Do they want to know?
- Patients in follow-up with primary oncologist or primary care physician

Ideas for Improvement

- Highlight studies that lead to FDA approvals
- Patient/Family facing thank you letters with data from trial sponsors that can be distributed
- Website/App that patients can access to learn about study updates (www.trialssummaries.com)
- Notifications that can be sent to patient or family member email/phone

Thank you to patients & research team!!!



References

- Al-shbool G, Latif H, Farid S et al. "Publication rate of registered clinical trials in lung cancer." 2019 ASCO Annual Meeting. Publication only.
- Liu X, Zhang Y, Li WF. "Evaluation of Oncology Trial Results Reporting Over a 10-Year Period." JAMA Netw Open. 2021;4;(5)e2110438.
- Tolunay PK, Erol C, Kahraman S, et al. "Understanding of Clinical Trials Among Patients With Cancer and Their Relatives." JAMA Network Open. 2025;8;(1):e2457020.