

Sensitivity Expectations of IMAT Investigators

The NCI Technology Research Advocacy Partnership (NTRAP) team appreciates that NCI IMAT principle investigators are conducting cutting edge cancer research that may directly or indirectly impact patient care. These projects often integrate patient samples, response data, or other forms of patient contribution. As such, IMAT stresses the importance of conducting research with respect for people living with cancer, and the use of appropriate language to credit the patient's contribution to research.

IMAT, in conjunction with NTRAP, is committed to encouraging language that demonstrates respect for the patient and members of the cancer community. This document is intended to guide the presentations and communications across the IMAT investigator community.

Examples of how best to convey research findings:

Example 1:

Recognize that treatments fail patients; patients do not fail treatments.

- Instead of: "Samples from six patients that failed to respond to treatment"
- Try: "Treatment was not found effective in X% of tumor samples from patients with Y cancer."

Example 2:

Remember that cancer patients are people with cancer, and are not defined by their cancer.

- Instead of: "The study included 25 EGFR mutants"
- Try: "The study included 25 patients with EGFR-mutated tumors" or "The study included samples from 25 patients with EGFR-mutated tumors."

Example 3:

Recall that a patient does not progress, but rather a tumor progresses. Focus on the tumor and not using the patient as a proxy for the tumor.

- Instead of: "The data was divided into patients that progressed and patients that responded"
- Try: "The data was divided into tumors that progressed with treatment, or tumors that responded to treatment."

Note: This language can also be applied to mouse models.

Following these guidelines we can better communicate data and share findings appropriately and with high regard for patient contributions to research.

These guidelines, as created by the advocate work group of the NCI Technology Research Advocacy Partnership (NTRAP), were adapted from the American Society of

Clinical Oncology's 2019 Language of Respect document. Thank you for your efforts in changing the lives of people with cancer.