A purpose of our study was to identify patient attitudes about clinical trials and factors that may predict trial interest and participation in order to inform future study design and improve the clinical trial referral system.

LIMITATIONS

This is a non-random sample, restricted to online users; subscribers to web-based support forums were the main participants.

Average age was 54 years, much younger than the mean for NHL, which is approximately 64 years at diagnosis. Only 6% of survey participants had Hodgkin's lymphoma (average age, 28 years).

We cannot tell from this survey if the factors associated with interest and participation in clinical trials are related to clinical necessity (higher-risk disease) or that (online / younger) patients are more proactive, or are more likely to be eligible for studies.

We are considering applying an improved version of our survey instrument to a random sample, pending feedback on this report.

FINDINGS

Participation (27%) in clinical trials is much higher than expected among this population. Commonly, 3-5% participation rates are cited among the general population with cancers.

Having Second Opinions, Second Evaluations of Pathology, and Consulting Outside Experts were all associated with significantly higher participation and interest in clinical trials.

Having a Second Opinion had the highest association with clinical trial consideration (107 of 168) and participation (58 of 107).

We should be encouraged by the high rate of clinical trial participation among those who have discussed studies with outside experts (62%) and their oncologist (60%), which suggests that making the discussion of clinical trials standard practice will increase enrollment rates. The Internet was reported as the primary way patients learned about trials.

We interpret concerns with randomization (56%) as a fear of receiving an inferior protocol: a form of study risk. Therefore perceived risk (33% + 56%) is the primary reason for declining to participate in a clinical trial in this cohort.

DISCUSSION

BACKGROUND

Enrollment in clinical trials is widely acknowledged to be insufficient to support progress against cancers (3-5%). As drug discovery accelerates, the evaluation bottleneck will get worse: Thousands of new agents, instead of hundreds, but the same number of patients and the same un-addressed obstacles to enrollment, which are undoubtedly delaying innovations.

ASSUMPTIONS

Patients are risk-adverse; tend to delay treatment decisions, which favors use of familiar, standard protocols when they get sick or need therapy.

To patients, participation in a clinical trial is a treatment decision. As such, study protocols must compare favorably to other study protocols and available standard therapies: be reasonable / appropriate treatment decisions for their clinical setting.

SETTING-BASED TRIAL DESIGN & DESCRIPTIONS

Rationales for participation - based on potentially meeting clinical needs and treatment objectives in common clinical settings - should be described clearly in study protocols ...

... basing study designs and descriptions on the objective of meeting needs and treatment goals (for ethical reasons), with awareness also of patient biases and hopes (for practical reasons):