Emerging Solutions: Cancer Information & Support Network Collaborative Advocacy Model.

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Background: In today's clinical trial arena interest in accrual and retention is extremely high among investigators. Although there have been various efforts to ascertain the worldview of prospective research participants, until recently no one knew why patients unfamiliar with the logistics and nuances of the research enterprise had difficulty making decisions about the risks and benefits of clinical trial participation.

The founder of CISN, a grassroots organization promoting awareness and action, spearheaded the advocacy effort to bridge the research gap and make patient-centered educational material a priority in the clinical trial informed consent process.

Hypothesis: Programs designed with advocate input in the informed consent process may enhance patient literacy, improve patient satisfaction, and advance public trust in the research enterprise leading to responsible increased accrual and retention.

Methods: CISN is introducing the medical community to an array of issues affecting patients considering participation in clinical trials: lack of literacy about research requirements; tissue donation; understanding the informed consent process; the importance of meaningful and full disclosure to patients, and strategies for promoting research integrity.

Discussion: Over the past several years' advocates have been integrated into the research setting. What is their role in the future and how can they help set new paradigms and models for informed consent? We address these issues and present various strategies that might be applied to other Cooperative Group trials so as to bridge the research gap, move research forward, and adopt the best course that serves the needs of the community, researchers, and patients.