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Establishing a standard practice to communicate trial results to study volunteer

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Studies consistently show that most clinical trial participants want to know what the research communities learned from their participation, yet most never hear from the sponsor or research site staff at all after a clinical trial has concluded. CISCRP has developed and tested a program to provide study volunteers with the results of their clinical trial. Working through our editorial panel of medical and health communications experts as well as patient advocates, CISCRP "translates" the technical results of clinical trials into scientifically accurate, non-promotional lay summaries written at a validated 6th-8th grade reading level. Prepared in printed, electronic and audio formats to accommodate different learning styles, the summaries are disseminated to volunteers via their investigative site as a way to fulfill researchers' ethical obligation to return trial results, and demonstrate to volunteers that they are respected as true partners in the clinical research process. This presentation will focus on establishing a standard practice to communicate trial results to study volunteers. We will explore the following: How lay language summaries fulfill the ethical obligation to return trial results to participants. Properly translate study results within lay summaries to ensure accurate return of results. Establish the need for multiple communication methods to return results and develop a standard practice for communicating lay language

Biography

Jill McNair has worked in the non-profit sector for over 20 years. She is the Senior Director, Patient Engagement at The Center for Information and Study on Clinical Research Participation (CISCRP). In this role, she oversees a team dedicated to helping sponsor companies provide lay language summaries to study volunteers. She also manages the planning, creation, and execution of CISCRP education and outreach programs; development and fundraising; marketing and public relations; and business development. She is passionate about providing education to the public so they can make an informed decision as to whether clinical research is right for them. Working at CISCRP affords her the opportunity to engage patients in the continuum of the clinical research process; whether it's providing education when they are in a physician's office or receiving a lay summary after they have given the gift of participation by participating in a study.

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