
Kenneth Getz, 2019, 414 pages, CISCRP, $24.99

Review by Norman M. Goldfarb

“The Gift of Participation: A Guide to Making Informed Decisions About Volunteering for a Clinical Trial, 3rd Edition” is a comprehensive handbook for potential clinical trial subjects and their caregivers. It is also an excellent primer for novice clinical research professionals (and their family members). It wouldn’t hurt if a few members of Congress knew something about clinical research, and this is the book to do it.

At 293 pages plus appendices, it contains more information than most study subjects think they want to know about clinical research, but they should read it anyway. Your grandparents can probably understand the book’s straightforward language. If they can’t, they probably won’t understand the language in an informed consent form.

The title of the book is drawn from the author’s leadership in generating appreciation for the gift that study subjects give society by donating their time, comfort and potentially their health when they participate in clinical trials. When we enroll a study subject, we owe them more than competence, regulatory compliance, and good ethics; they also deserve our respect, consideration and gratitude.

In 2003, to help bridge the communication gap between the clinical research enterprise and the public, Mr. Getz founded the non-profit organization CISCRP, the Center for Information & Study on Clinical Research Participation (http://www.ciscrp.org/), the most important organization working in this area, with the possible exception of the FDA.

The third edition of the book includes a new forward by cancer survivor and Medical Hero, Meisha Brown; a new chapter on the patient engagement movement and new ways that patients, their families, and health care providers are getting involved as partners in the clinical research process; a new section on precision medicine and the use of genetic information and bio-markers in clinical research; a new section on changing legislation and guidelines about expanded access and the right to try for patients who are not eligible for a clinical trial but wish to inquire about gaining access to a new investigational treatment; a new section on new approaches to improving study participation convenience, including the use of home nursing networks, concierge services, hybrid and virtual clinical trials; and a new section on receiving plain language clinical trial results.

The book includes 11 chapters:

- Recognizing the Gift of Participation
- Why Clinical Trials are Conducted
- Why People Choose to Participate
- A Long, Complex, Risky and Very Human Enterprise
- It’s About You: The Patient Engagement Movement
- Education Before Participation: Do Your Homework

This book has been selected for

**The MAGI Clinical Research Bookshelf**

Essential reading for clinical research professionals
• Where to Find Clinical Trials
• Giving Your Informed Consent
• Historical Events that Have Shaped Study Participation Protection
• Considerations for Special Populations
• What to Do When Things Go Wrong

Reviewer
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