

A systematic literature review to identify ethical, legal and social responsibilities of nonprofit organizations when funding clinical trials in pediatric cancer

Vasiliki Rahimzadeh¹, Susan Wolfert², Victoria Buenger², Cindy Campbell², Robin French², Donna Ludwinski³, Amy Weinstein², and Caitlyn Barrett²

¹Stanford University

²Coalition Against Childhood Cancer

³Solving Kids' Cancer

April 6, 2022

Abstract

Nonprofit organizations (NPOs) play critical roles as funding sources, research partners, and disseminators of emerging drug developments in pediatric cancer, yet the literature offers limited understanding or guidance of ethical best practices and processes. We conducted a systematic search for peer reviewed articles, commentaries, newsletters, and white papers indexed in the PubMed and Web of Science databases to identify the ethical, legal, and social responsibilities of NPOs to i) patients/families, ii) researchers, iii) sponsors, and iv) donors when funding clinical trials. Fifty-four articles met the inclusion criteria. Minimizing conflicts of interest, ensuring transparent reporting of trial endpoints, and communicating with families about trial opportunities emerged as key themes. We identified critical gaps in the literature related to negotiating research partnerships, setting trial priorities and establishing best ethical practices in the emerging field of venture philanthropy. Results informed points to consider for NPOs when funding pediatric cancer clinical trials going forward.

Hosted file

CAC2 manuscript_PBC submission_4.5.22_.docx available at <https://authorea.com/users/474342/articles/564227-a-systematic-literature-review-to-identify-ethical-legal-and-social-responsibilities-of-nonprofit-organizations-when-funding-clinical-trials-in-pediatric-cancer>

Hosted file

Figure 1_PBC.docx available at <https://authorea.com/users/474342/articles/564227-a-systematic-literature-review-to-identify-ethical-legal-and-social-responsibilities-of-nonprofit-organizations-when-funding-clinical-trials-in-pediatric-cancer>

Hosted file

Figure 2_PBC.docx available at <https://authorea.com/users/474342/articles/564227-a-systematic-literature-review-to-identify-ethical-legal-and-social-responsibilities-of-nonprofit-organizations-when-funding-clinical-trials-in-pediatric-cancer>

Hosted file

Figure 3_PBC.docx available at <https://authorea.com/users/474342/articles/564227-a-systematic-literature-review-to-identify-ethical-legal-and-social-responsibilities-of-nonprofit-organizations-when-funding-clinical-trials-in-pediatric-cancer>

of-nonprofit-organizations-when-funding-clinical-trials-in-pediatric-cancer