



TO: Task Force on Research Specific to Pregnant Women and Lactating Women
February 2018

FROM: Genetic Alliance, Expecting Health
www.ExpectingHealth.org

The below comments serve as recommendations for effective communications strategies with women, families, and other relevant stakeholders on the critical issue of ensuring that medical research addresses questions from women in pregnancy, postpartum, and early childhood. As such we appreciate your considerations of our organizational knowledge and recommendations below.

Background

At Expecting Health, we know that women understand and want to be informed about complex concepts, but it is imperative that we prioritize our use of clear messaging to break down information. With decades of experience in maternal health communications and patient engagement in research, we know how to access women and the issues they care about most. Moms tell us time and time again that they want the best lives for their children, understand that their health greatly impacts outcomes for their children, and therefore are focused on improving behavior and increasing health knowledge during and post-pregnancy. For pregnant and lactating women with medical needs, it becomes all the more important to understand how to increase chances for a healthy pregnancy and empowering breastfeeding experience. There is no population for which more market and behavior data is collected than pregnant women. Because women are changing their behaviors and are interested in improving health behaviors, pregnancy is the ideal time to focus on informed participation, change in knowledge, and messaging to informed decision making.¹ Healthcare and research can capitalize on what the consumer and product market already knows around participation in this population and learn from behavior to build trust, lines of communications for research and clinical trials, and effective feedback gathering.

Recommendations

1. Mechanisms for stakeholder involvement, input, feedback collection, and subsequent iteration should be incorporated throughout the research process. Pregnant and lactating women should be invited to be leaders—from the beginning—to aid in crafting the most valuable research questions, more effective recruitment, and better, faster integration and dissemination of results.

¹ Tierney, M., Odea, A., Danyliv, A., Noctor, E., McGuire, B., Glynn, L., . . . Dunne, F. (2015). Factors influencing lifestyle behaviours during and after a gestational diabetes mellitus pregnancy. *Health Psychology and Behavioral Medicine*, 3(1), 204-216. doi:10.1080/21642850.2015.1073111.

2. Messages need to be consistent across all audiences so that healthcare providers, patients, and communities receive clear messages and multi-pronged communications strategies routinely reach all individuals. Involvement of all players will support efficiency in building a new culture for research in prenatal practice.
3. The expectation for involvement in research should be based in ongoing relationship and mutual trust; not consent and single-use participation. Involving women and their trusted informants is critical for partnership and trust building.
4. The research paradigm must allow for self-reported data, and both respect and trust women's knowledge as part of their medical landscape.
5. In order to see impact on the quality and scope of the population, it is essential that communications, research questions, and research processes are framed from a lens of health equity. Nuanced variables on trust, barriers, and benefits to participation in research for vulnerable populations must be acknowledged fully and throughout the process.