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Missing the 'Target': Preventing the Unjust Inclusion of Vulnerable Children for Medical Research Studies

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Missing the 'Target': Preventing the Unjust Inclusion of Vulnerable Children for Medical Research Studies

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Abstract

The central purpose of medical research on children is to generate new knowledge that can improve children's health, subject to ethical standards that promote justice. Incorporated in U.S. law, international law, and European Union law, the Justice Principle prohibits targeting in medical research, which is the selection of research subjects because of their manipulability and compromised position, rather than for reasons directly related to the problem being studied. Unfortunately, medical research studies involving children have too often violated the Justice Principle, by targeting children in a compromised position due to their health status and vulnerable to manipulability because of their race and class. For example, a U.S. physician implanted pacemakers in fifty-five healthy African-American children resulting in disability, while a drug company tested an unapproved antibiotic in Nigerian children suffering from meningitis causing the death of eleven children, although there was a proven therapy available to the children.

To prevent the targeting of these children, I recommend the development of a Vulnerability and Equity Impact Assessment tool (VEIA) similar to the Health Equity Impact Assessment tool to determine whether it is just to select children from particular groups as research subjects. Specifically, the VEIA will measure the societal burdens borne by children as a result of their race, class, and/or health status that compromises their position and makes them vulnerable to manipulability, the potential risks of the research such as physical and psychological harm, and the prospective benefits from the research such as guaranteed access to the therapy if it works. The research study using children from particular groups should not be approved for funding and/or the drug should not be approved for use, unless based on the VEIA, the researcher shows that the benefits to children from these particular groups outweigh the burdens and the risks.

Keywords: medical research, children, justice, vulnerable

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