

Clinical Lactation Code Regarding Informed Consent for Research Participation or Case Studies

Informed consent for research protects participants in research projects and/or case illustrations. Participants in research studies or case illustrations must give informed, written consent before they become part of a study or their confidential information is used in a case study.

For research studies, participants must understand the purpose of the research, how long it will last, and their right to decline or withdraw from the study at any time. They need to understand if there are any consequences of withdrawing, and if being in the study will be painful, or cause any discomfort. Participants need to understand how their privacy and confidentiality will be protected, and what the limits to confidentiality are (such as when a mother or her baby are in danger). Participants also need to know if they will receive anything for participating in a study, and the name of someone they can contact if they have any questions.

When mothers are described in a case study or illustration, identifying details should be omitted unless they are essential. Mothers have the right to know what will be said about them before publication, and that their names, photos, or any identifying information are obscured unless they have given explicit, written permission for that information to be used. Mothers should also be told that an article about them will also appear online.

Mothers must also give written consent before photos of them or their babies can be published in the journal, and they need to be told what steps will be taken to preserve their confidentiality (e.g., cropping a photo so that the mother's face does not show or pixilating an image over the mother's face). Participants should know that photos that are part of case illustrations will also appear online.