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Residents' awareness and attitudes about an ongoing community-based genome cohort study in Nagahama, Japan

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This study examined residents' attitudes toward an ongoing, real genome cohort study based on a community. The Kyoto University Graduate School of Medicine and the city of Nagahama initiated the Nagahama study for comprehensive human bioscience to promote the health of the citizens of Nagahama, develop community-based genomic-epidemiologic studies, and create a biobank. The Nagahama city government enacted an ordinance to manage the study. The mission was to prioritize the dignity of citizens. After the launch of the genome cohort study, in November and December 2009, a self-administered questionnaire survey was conducted with 2500 randomly sampled residents aged 30-74 years living in Nagahama, Japan. Responses were received from 1363 people, 187 of whom had already participated in the study. Although the local government and researchers disseminated information through leaflets and citizen-information papers to every household, sent notices by personalized letter, and held symposia and other meetings, 66% of males and 47% of females first became aware of the study when they received our questionnaire. Half of the participants understood it as a medical study involved genetic analysis. Their attitudes were significantly associated with the desire for an extensive health check-up. Particularly, positive aspects were associated with a high health consciousness in males and participation in community activities in females. Although promoting a community-based genome cohort study requires a huge effort, popularizing it is essential. Actions are vital for both monitoring public awareness and attitudes at a community level and for keeping the channels of communication open.

Biography

Miyamoto Keiko is a student in the Medical Communication Department at Kyoto University Graduate School of Medicine, Japan. She is interested in the public understanding of science, risk communication, and social relations.

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