Ethical, legal, and social implications of human genome studies in radiation research: a workshop report for studies on atomic bomb survivors at Radiation Effects Research Foundation

The Radiation Effects Research Foundation (RERF) held an online international workshop in December 2020 to discuss the ethical, legal, and social implications of future genome studies.

Since human genome sequencing has become more practical for use in research in recent years, RERF is planning to sequence the genomes of family groups called "trios" (indicating parents and a child, with at least one of the parents being an A-bomb survivor) to examine genetic effects from A-bomb radiation.

Such research can involve effects on society, as well as issues of an ethical and legal nature, and therefore consideration of such issues and communication with A-bomb survivors and their families about consent issues are necessary. The workshop delved into frequently addressed issues arising in genome research—protection of personal information, use of blood and other biosamples from deceased research participants, return of study results to participants, and contributions to progress in science as well as public health and welfare.

The workshop's broad-ranging discussions led to realization of the necessity to engage in our studies and research based on such concepts as "trust," "compromise," and "relationship building," with particular focus on RERF's relationships with those who cooperate in our studies, in other words our stakeholders.

The discussions concluded with the recognition that procedures must be put in place to establish and maintain these important concepts to ensure the successful, consensus-based implementation of RERF genome research.

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RERF's objective with this brief outline is to succinctly explain our research for the lay public. Much of the technical content of the original paper has been omitted. For further details about the study, please refer to the full paper published by the journal.