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Supportive Information Governance framework for community building

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Taiwan's policy to develop a —biomedical technology island encompasses three major elements: a center for excellence in clinical trials; the national health information platform; and the Taiwan biobank. The current research has compiled the miscellaneous challenges and suspicions of human rights and civil organizations towards biomedical research, as well as their proposals, and analyzed the views of the public toward the national policy for an integrated biomedical information system. In particular, it has carried out a national public opinion survey in order to assist in drafting a direction for policy. The investigation reported here utilized telephone interviewing in the period December 2 through 9, 2008, and completed interviews with 2446 persons; this achieves representation of the population with a level of confidence level of 95%, with a sampling error of no more than $\pm 1.98\%$. The investigation discovered that most of the Taiwan public is concerned for the government's utilization of health information, and realizes the importance of the health information policy for provision of related information to the public. However, in the aspect of how the material is processed, they trust the government more than the research organizations. This seems to mean that the public expects the government to take on the responsibility for management of the materials and information; and under the condition that the public generally does not have trust in the confidentiality maintained by the related organizations, they will however support government utilization of individual private health information if given the precondition of respect of informed consent. This research concludes with a recommendation to the ELSI section of the Taiwan Biobank, that the government must itself take responsibility for the formulation of policy, rather than delegating it to a research team. Moreover, there must be bottom-up participation by the public, in the creation of relevant ethical mechanisms, in order to achieve the potential of recreating Taiwan as an island center of biotech research.