## Chapter 9: Research Access

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An individual entrusting a government agency with sensitive, personally identifiable information has a right to expect that the agency will handle the information with the care and confidentiality it deserves. For example, the Commission asserts that the privacy interests of a record subject regarding personally identifiable medical information clearly is greater than the public's right to inspect that data.

The Commission believes, however, that there may be certain situations in which a significant public purpose would be served by the examination of such data by researchers. Without question, society has benefited immeasurably by the advances in medical research over the past decades. Yet many of these advances would not have been possible without access to personally identifiable data.

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The Commission feels that a mechanism should be established to permit access to personally identifiable information for meritorious research projects while, at the same time, protecting the privacy rights of the records subjects. The Commission believes that the best way to accomplish both goals is to require researchers to meet certain specified conditions prior to the release of personally identifiable data. First of all, a researcher should be required to provide a written statement to the custodian explaining the purpose of the research project, the nature of the records needed to achieve the project's goals, and the specific safeguards that will be taken to protect the identities of the records' subjects. The Commission also firmly believes that the researcher should agree that he will not contact the records subjects in any way without the prior approval and monitoring of the custodian. Third, the Commission feels that the data should not be released unless the custodian is convinced of the adequacy of the researcher's proposed safeguards to prevent the public identification of the records subjects. Finally, the researcher should be required to execute an agreement with the custodian delineating all of the above points and attesting to the fact that failure to abide by the conditions of the agreement would constitute a breach of contract.

Governor's Information Practices Commission, Final Report at 545-46 (1982). The language of the amendment and the rationale supplied by the Commission indicate that researchers may use this method to gain access to personal records even where a law other than the Public Information Act bars disclosure. Thus, the amendment has general effect beyond the PIA.