

Defining the Limits of Freedom of Inquiry: The Ethics of Disclosing Personal Information held in Government Archives

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It is generally conceded that the principle of freedom of information, or the public's "right to know," constitutes a legitimate constraint on the individual's right to information privacy. The public interest in an informed citizenry and an accountable government requires that when the individual's right to privacy becomes an impediment to the realization of the public's right to know, the former must give way to the latter. The question is, how broadly (or narrowly) should the public's interest in personal information be defined? We can accept that the public interest is served by the disclosure of government-held personal information when it facilitates citizens' oversight of governmental affairs. But is the public interest equally served by the disclosure of personal information for other worthy, though less tangible ends, for example, furthering the purposes of research? Put another way, does society's need for knowledge amount to a justifiable constraint on the right to privacy?

The question is one which archivists increasingly face in administering access to personal information held in government archives. If we translate this into the language of archival ethics, the question becomes, how do we balance research and privacy values when researchers seek access to public records containing personal information? Which of the two competing interests, the research community's in knowledge, or the individual's in privacy, should be given primary consideration? These questions will be explored here in the context of social science research generally, and more particularly, research in this area that requires the use of government-held personal information as a source of data; information that was obtained from, or about, individuals on an earlier occasion and for a different purpose.

The traditional rationale for research serves partly to answer, partly to deflect the question whether research involving the use of personal information is morally permissible in a given case. Freedom of enquiry in the pursuit of knowledge is a principle typically expressed both in its own right, and in opposition to the regulation of research. To the extent that restrictions on research involving the use of personal information would make some studies impossible to perform, some researchers argue, such restrictions infringe on the scholar's right to illuminate still mysterious regions of human behaviour. The obligation to advance knowledge, though, is only one among a large number of social obligations that affect researchers; these other obligations can easily

impose alternative and conflicting imperatives. Moreover, there is a critical distinction between the freedom to conduct research and the freedom to involve human subjects in research; the second freedom is considerably more limited than the first. Freedom of enquiry, however important, does not lend any special legitimacy to practices considered otherwise disrespectful of persons.

If the principle of academic freedom does not, in itself, adequately justify research that requires the use of personal information, how else might we determine whether such research is morally permissible? A typical approach is the utilitarian one, which draws on the beneficial consequences that derive from research. Here, the principle of beneficence is used to ascertain classes of actions that are morally permissible to achieve beneficial ends; ethical dilemmas are resolved by balancing the risk of harm to subjects against the potential benefits of research.

The risk-benefit approach would appear to provide a more objective means of weighing the comparative values of research and individual privacy. As a model for evaluating social science research specifically, however, it is flawed on a number of counts. First, some critics question whether it is appropriate to justify such research in terms of the social benefits it promises to produce. The model is drawn from bio-medical research, in which specific improvements in health care delivery or cost reductions can be cited as important social benefits. It is not really possible to invoke comparable benefits in performing risk-benefit assessments in social research, since much of it is aimed primarily at the acquisition of knowledge and only secondarily, if at all, at the beneficial applications which may result from that knowledge.

Secondly, how do we determine a common standard in terms of which to compare harmful and beneficial consequences? The judgements that can be made ahead of time concerning the potential harm a research project presents to record subjects tend to be based on untested assumptions about record subjects' feelings on the matter, or on the archivist's (or researcher's) own sense of right and wrong. The notion of harm implies an evaluative framework for assessing damage to individuals and to social groups, one that, according to Donald Warwick, "entails fundamental assumptions about the nature of persons and society, about the individual and collective conditions constituting well-being, or its absence, about what is most and least valued by persons or groups, and about the specific impact of research on these constituencies."¹ However much may be assumed about the harms and benefits record subjects would themselves see as important to them, very little is actually known about such matters, because most of the factors that must be considered are intangible and subjective: "Should the term [harm] be restricted to physical consequences that are damaging and irreversible, or should it also embrace impermanent and less dramatic psychological effects? Legal effects? Economic effects?"²

Risk-benefit analysis is most effective in situations where the total benefit or cost expected from a particular course of action can be identified and measured with precision. Such precision is unrealistic in the evaluation of research in the social sciences and humanities, primarily because the harmful consequences that can be reasonably predicted are more likely to be cumulative in nature; these effects may manifest themselves, for example, in a reduction in the amount of private space possible for individuals within society and in a gradual erosion of the societal trust on which the integrity of certain social institutions and social relationships depend. Since cumulative

effects are not easily proven, however, we frequently fail to take them into account in evaluating research and tend to limit our calculations of harm to the individual record subjects; although we are quick to point out the cumulative beneficial effects of increased knowledge.³

An alternative to the risk-benefit approach is offered by Herbert Kelman, who advocates a rights-based analysis, one based on a description of a particular action, rather than on the prediction of its consequences.⁴ In this approach, which I would also advocate, the ultimate criterion for the moral evaluation of research involving the use of personal information is "consistency with human dignity," defined as "the status of individuals as ends in themselves, rather than as means towards some extraneous ends," a definition that derives from Kant's categorical imperative to, "act so that in your own person as well as . . . every other you are treating mankind . . . as an end, never merely as a means."⁵ The crucial point in a rights-based analysis is that, although the origin of such rights is ultimately rooted in harm-benefit considerations, these rights become "functionally autonomous . . . [t]hat is, the right has moral force regardless of whether, in any given case, it can be *demonstrated* that its violation would cause harm."⁶ According to Kelman, we take or avoid taking certain actions, defined by general moral principles, not only to avoid causing harm, but also to conform to and maintain the integrity of a right because of the presumed, long-term systematic consequences of its violation.

Invasion of privacy generally, and violation of confidentiality specifically, may be viewed as injuries of a special type as well as conditions that leave people vulnerable to the possibility of harm. Invasion of privacy cannot be described as harm in the obvious sense of a lasting injury or measurable damage to the record subjects. It can, however, be subsumed under the category of injuries which the philosopher Alisdair MacIntyre designates "moral wrongs," acts that subject people to the experience of being morally wronged, whether or not their interests are damaged in specifiable ways.⁷ Research that is invasive of individual privacy is wrong because it by-passes the normal decision-making capacities of individuals and interferes with the voluntary nature of their actions.

Many of the ethical problems associated with research involving the use of personal information could be reduced, and perhaps eliminated, if the informed consent of record subjects could either be obtained or presumed, because such consent satisfies the moral requirement of respect for persons. With respect to research uses of administrative records, the question is whether we can assume tacit or implied consent on the part of the individual who originally supplied the information, to subsequent uses of that information. The answer, in most cases, is that any such assumption would be erroneous. Certain government services require that individuals provide what is often extremely sensitive personal information about themselves. Since they must disclose that information in order to receive benefits or compensation, for example, medical coverage, welfare or unemployment insurance, there is some question whether such disclosure can be taken as "implied consent" to any use of that information; certainly it has not been given freely, which is what consent implies. Furthermore, assuming individuals did not know that the information they disclosed about themselves would be used in a different context, their capacity to protect their interests was clearly impaired when they consented to provide the information in the first place.

The invasion of privacy that results from the failure to obtain consent for a clearly different use of the information from the one originally agreed to may be exacerbated by the breaking of a promise of confidentiality that was made when the information was originally collected. The moral rule against breaking a promise of confidentiality is rooted in respect for individuals' autonomy over information about themselves, as well as respect for the integrity and importance of the confidential relationship in which such information is shared. In particular kinds of confidential relationships, for example, the relationship between therapist and patient, or between social worker and client, the principle of confidentiality is defended on the grounds that it provides individuals with a safe area into which they can enter in order to seek help or obtain justice. Such a relationship imposes on the person who receives confidential information an affirmative duty with respect to the interests of the person who discloses it. The central affirmation of the relationship is that the vulnerability of the patient or client will not be exploited; the failure to protect the client's interests constitutes a form of abandonment.

The Kantian argument that people should be treated as ends in themselves and not merely as means requires that we show respect for the humanity and dignity of all persons; and that we treat each other in accordance with those principles that express conduct which we believe should be universally practised. The principle of confidentiality is a specific application of the principle of promise-keeping in ethics generally. To break a promise is implicitly to condone promise-breaking and, thereby, contribute to the erosion of promise-keeping as a principle. To determine whether it is acceptable to break a promise, we need to ask ourselves what the world would be like if the principle of promise-breaking became part of everyone's nature. Would we choose to live in a world in which individuals were routinely permitted to break promises, if doing so would produce knowledge they thought was worth having?

The moral premises justifying confidentiality do not, of course, foreclose debate over such questions as whether the promise should have been given in the first place; whether it is binding; and what circumstances justify overriding it. A promise of confidentiality can be overridden, for example, when the withholding of information could endanger the lives of the individuals themselves or innocent third parties. The crucial point is that in the absence of a competing moral imperative requiring disclosure, such promises should be maintained.

A rights-based analysis requires that the justification for research involving the use of personal information should be developed within a framework of moral reasoning that focuses on principles shared between people and to which we can imagine people contractually agreeing. In making that judgement, we would do well to keep in mind the critical distinction which Christian Bay makes between a "social privilege" and a "human right"; and ask ourselves whether, in the final analysis, the freedom to conduct research that requires the use of personal information should more properly be considered a social privilege than a right. According to Bay,

"Right" refers to a protected freedom. "Human right" refers to a kind of freedom that can be, and therefore must be, made available to and protected for all the people in a given society. A freedom that cannot be extended to all is an example of a "social privilege" ...[and] in a free society a privilege must yield whenever it demonstrably becomes an obstacle to a fuller protection and expansion of human rights.⁸

If we accept Bay's characterization of the distinction between a social privilege and a human right, it follows that, as a general precept, the needs and interests of research should yield to the needs and interests of personal privacy, when these two values conflict. Unless the gain promised by research is very great relative to the loss of individual autonomy, it is unlikely that the community as a whole will accept ethical standards that give higher priority to research than to respect for human subjects.

For most kinds of research involving human subjects, certain individual rights — the right to be fully informed about the precise nature and purpose of the research in which participation is sought, so that consent may be given or withheld advisedly; the right to know about the risks and benefits involved; and the right to assurance that any information disclosed will remain confidential — are generally accepted prerequisites for conducting the research. In research that requires the use of records held in government archives, individuals are incapable of exercising these rights because they are unaware that records concerning them are being used for research purposes, and because it is either impossible or impracticable to obtain their consent. It is therefore critical that archivists intercede on behalf of record subjects to ensure that violations of privacy are minimized, and wherever possible eliminated.

Equally critical is the recognition that ethical review of research projects implicating privacy values is a collective rather than an individual responsibility. Most public agencies that fund research—among them, the Social Sciences and Humanities Research Council, the Canada Council, and the Medical Research Council—now require that research projects involving human subjects be approved by a standing ethics review committee (or board) of the institution employing the principal investigator, before projects can be considered eligible for funding; and they have established guidelines under which such a review committee should operate. The guidelines recommend, for example, that the review committee be established under the authority of the head of the institution and have a mandate to review all research projects involving human subjects; that its membership include, in addition to the relevant subject specialists, a lay representative from the community and a lawyer; and that it establish procedures for the continuing review of research projects that have been approved.

Public research funding agencies defend the institutional review requirement on the grounds that, as trustees of public funds, such agencies have a responsibility to ensure that the activities they support respect the rights of the public they serve. As trustees of government records, government archives are invested with a similar responsibility and should therefore give serious consideration to establishing procedures for institutional review based on the model just described.⁹

If an archives were to establish an institutional review committee with a mandate to evaluate research projects implicating privacy values, what sort of guidelines should it follow in making access decisions? Given its obligation to protect the interests, autonomy and rights of record subjects, and to ensure that harm to such individuals is avoided, the committee normally should permit access to restricted records only when the use or disclosure would not violate a legitimate expectation of confidentiality on the part of the record subjects. In determining whether or not such an expectation is legitimate, the committee should ask itself a number of questions: Were record subjects informed, at the time the information was collected, that the information they disclosed

would be held confidential by the agency? Is there documentation supporting such a promise? Do any explicit statutory or other provisions exist that protect the confidentiality of the information? Do these provisions permit disclosure for research purposes? Can any precedents be cited for permitting or denying access for such purposes, and can these be considered determinative? Are the provisions specifically formulated for the protection of record subjects, or are they designed to protect generally defined agency interests during the active life of the records? If no explicit confidentiality provisions exist, is there evidence to support an implicit expectation of confidentiality? For example, was the information disclosed in the context of a socially recognized confidential relationship? A legitimate expectation of confidentiality may also be presumed when the information is of a particularly sensitive or intimate nature.

The review committee should have the power to determine whether, in certain compelling cases, it is ethical for a presumption of confidentiality to be waived; if the record subjects may reasonably be supposed deceased, for example, the threat to individual privacy may be sufficiently reduced to merit disclosure for research purposes. In deciding whether disclosure is justifiable in a given case, the committee would need to weigh the sensitivity of the information against the expectation of any *tangible* or *compelling* social benefit, primarily to the record subjects, and secondarily to society as a whole. Although the potential benefits of research are a legitimate consideration, in balancing them against potential risks the committee would have to give fuller consideration to the risks disclosure would pose—both individual and collective—to physical, psychological and humane values.

Whatever decisions the review committee takes with respect to granting or denying access, it must be prepared to define and defend the moral principles on which its decisions are based. The obligation to protect record subjects does not, for example, give such a committee a licence to reject research proposals for any of the following reasons: fear of embarrassment, either to the archives or the record-creating agency, from the publication of research results or out of fear of general political controversy; a political judgement that research results would, if published, harm a group, organization or community and fear of the political consequences which might follow that harm; or a judgement of the competence or legitimacy of a research investigator rather than of the particulars of a research programme. Such issues are more appropriately addressed in other social policy forums, for example, through the granting agency, peer review or the political process at various levels.

When the Society of American Archivists drafted its definition of an archivist in 1984, it asserted that “the archivist is the trustee of the present and the past for future generations . . . a steadfast keeper of the records held in trust.”¹⁰ In their fiduciary capacity, archivists are charged with the responsibility to safeguard the integrity of the records in their custody. For government archivists, such a responsibility carries with it an implicit obligation to safeguard the integrity of the contractual relationship that exists between citizens and their government which the records document; and to intercede on behalf of record subjects in administering access to such records so as to ensure that citizens’ rights are protected under the terms of that contract.

In the same way that restrictions on the admissibility of evidence impede police work, or limits on the use of confidential information hamper banks, enforcing strict ethical guidelines for the administration of access to personal information in government

archives will undoubtedly hinder and perhaps render valuable research impossible. Such a consequence is hardly welcome. But any ethical stance constrains someone's freedom; that does not mean the stance is unreasonable or unjust. In the end, our acceptance of limitations on the pursuit of knowledge in order to promote a greater common interest—respect for human dignity—is what distinguishes us as moral beings.

Notes

- * This article is a revised version of a paper presented at the Annual Conference of the Association of Canadian Archivists in Victoria, British Columbia, 31 May 1990. It is based on Chapters 6 and 7 of *Without Consent: The Ethics of Disclosing Personal Information held in Public Archives*, which will be published in 1991 by Scarecrow Press.
- 1 Donald P. Warwick, "Types of Harm in Social Research," *Ethical Issues in Social Science Research*, eds. Tom L. Beauchamp *et al.* (Baltimore, 1982), 103.
- 2 Tom Beauchamp, "Introduction," *Ethical Issues in Social Science Research*, #24.
- 3 Warwick, "Types of Harm in Social Research," *Ethical Issues in Social Science Research*, #104.
- 4 Herbert Kelman, "Ethical Issues in Different Social Science Methods," *Ethical Issues in Social Science Research*, eds. Beauchamp *et al.*, 42.
- 5 Immanuel Kant, *The Fundamental Principles of the Metaphysics of Ethics*, trans. O. Manthey-Zorn (New York, 1938), 47.
- 6 Kelman, "Ethical Issues in Different Social Science Methods," *Ethical Issues in Social Science Research*, eds. Beauchamp *et al.*, 89.
- 7 Alisdair MacIntyre, "Risk, Harm, and Benefit Assessments," *Ethical Issues in Social Science Research*, eds. Beauchamp *et al.*, 177.
- 8 Christian Bay, "Access to Political Knowledge as a Human Right," *Government Secrecy in Democracies*, ed. Itzhak Galnoor (New York, 1977), 23.
- 9 A detailed description of the kind of institutional procedures that could be established for the ethical review of research projects requiring the use of personal information held in public archives is included in Chapter 7 of *Without Consent: The Ethics of Disclosing Personal Information Held in Public Archives*, (New Jersey: Scarecrow Press, [forthcoming 1991]).
- 10 "Archivist: A Definition," *S.A.A. Newsletter* (January 1984), #4.