PRIVATE INTERESTS IN THE PUBLIC DOMAIN

PRIVATE INTERESTS IN THE PUBLIC DOMAIN:

PRIVACY AND CONFIDENTIALITY IN OBSERVATIONAL HEALTH RESEARCH

By

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ABSTRACT

The expectation of privacy and confidentiality in health care presents a unique dilemma for public health interests. A great deal of observational health research such as epidemiological studies, disease surveillance, and quality assurance depends on access and use of personal information in the absence of individual consent. Understandably, this raises concerns about personal privacy since sensitive disclosures of information can result in harm such as stigma, discrimination, and loss of socio-economic goods. However, the issue has been largely framed and discussed as a dichotomy: the privacy interest of the individual versus the social interest in research. An individualist paradigm informed by a traditional liberal conception of privacy that emphasizes autonomy drives this dichotomy and inevitably leads to an intractable conflict. In this thesis, I attempt to re-frame the issue by moving away from individualism in shifting the focus towards confidentiality which is relational and founded on trust. I argue that confidentiality is broader than the concern for individual privacy and is thus capable of capturing other relevant interests, such as collective and social interests. I advance a broad conception of confidentiality grounded in a mixed deontic-consequentialist moral framework that can account for respect for persons and social interests.

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-- Introduction --

Within the context of observational health research[1], the issues of privacy and confidentiality continue to be dominant concerns. This is in large measure due to advancements in technology, particularly the development of sophisticated computer-mediated technologies which permit the collection, storage, use and dissemination of voluminous amounts of personal information, which raise new and interesting challenges with respect to personal privacy. Observational health research can involve secondary uses of clinical health information, large, multi-disciplinary teams of researchers across many sites, and in many cases, can be approved by institutional Research Ethics Boards in the absence of individual consent. In Canada, privacy legislation aimed at regulating the conduct of research, alongside research guidelines such as the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*[2] (TCPS) instituted by the federal funding agencies, stipulate the conditions requiring consent for information access, use and disclosure, as well as the circumstances when it is appropriate to waive the need for individual consent.[3] However, there is sufficient flexibility within those

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[1] Research studies and investigations that do not involve experimentation on subjects; in this thesis, observational health research implies only the use of information about patients and subjects.

[2] Medical Research Council of Canada (MRC), Natural Sciences and Engineering Research Council of Canada (NSERC), Social Sciences and Humanities Research Council of Canada (SSHRC), *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.* 1998 (with 2000, 2002 and 2005 amendments).

[3] In Canada all the western provinces have health-specific privacy legislaton: BC – Freedom of Information and Protection of Privacy Act; Personal Information Protection Act (FIPPA, PIPA); Alberta – Health Information Act (HIA); Saskatchewan – Health Information Act (HIA); Manitoba – Personal Health Information Act (PHIA). The Health Information Protection Act (OHIPA) of Ontario came into effect on November 1, 2004. The remaining provinces and territories have provincial legislation that regulates access to personal information in the public sector, and medical records usually fall within its purview. For

parameters to variably interpret the need for consent[4], leading to concerns about the privacy of one's health information. Canadian opinion polls suggest that the public is increasingly worried about the loss of medical privacy.[5] A recent Canadian study reported that "virtually all respondents felt protection of the privacy of their personal information was somewhat (23%) or very (74%) important. Fifty-six percent expressed increased concern over their privacy in the past five years."[6] Surveys in the United States, Australia and the United Kingdom have reported similar conclusions.[7] At the same time, those surveys also report that the public values health research and is willing to compromise some privacy to this end.[8] This tension between individual privacy interests and the societal interest in health research is a source of ongoing debate in bioethics.

Violations of privacy and confidentiality during the course of research, inadvertent or not, can result in devastating consequences for the individuals to whom the information pertains. Beyond sustaining the wrongfulness of a harmless invasion or breach, a serious violation can result in embarrassment or shame, stigmatization, and loss of social or economic goods, such as when health insurance is denied based on prejudicial

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example, Quebec's provincial Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information governs access to health records since these are in the custodial care of a Public Official.

[4] Willison et al. "Access to Medical Records for Research Purposes: Varying Perceptions Across Research Ethics Boards" (2008) 34:4 *Journal of Medical Ethics* 308.

[5] OIPC Stakeholder Survey, Alberta, 2003.

[6] Willison et al "Alternatives to Project-specific Consent for Access to Personal Information for Health Research: What is the Opinion of the Canadian Public?" (2007) 14:6 *Journal of the American Medical Informatics Association* 708.

[7] M.R. Robling et al. "Public attitudes towards the use of primary care patient record data in medical research without consent: a qualitative study" (2004) 30 *Journal of Medical Ethics*104-109. I will confine my analysis to western liberal democracies, although many of the issues under consideration here are relevant to health research taking place in other political contexts.

[8] Willison et al, 2007.

test results. Moreover, subjects can be harmed intangibly, though no less seriously, by suffering an attack on their dignity.

The health sector attempts to mitigate privacy threats by ensuring adequate security systems and processes are in place to protect individual privacy, in compliance with law and policy. In both clinical care and research, the public is given assurances that the privacy and confidentiality of their information is maintained. However, privacy is not equal to having security, nor is it the equivalent of confidentiality.

It is of particular interest that in common discourse and in the ethics literature we often refer to the 'privacy and confidentiality' of health information, as if to state one and not the other would provide insufficient coverage. To have adequate protection, one apparently needs to have both privacy *and* confidentiality, although it is rarely made explicit what is afforded (or missed) by each one, motivating the joint protection. Privacy is the wider concept; having adequate privacy protection should cover us. Yet confidentiality is consistently tagged to privacy, suggesting that there must be some additional value in having the confidentiality of one's health information maintained beyond the protection of privacy. How do privacy and confidentiality differ and does it make a difference in this debate?

This thesis is an examination of confidentiality in the context of observational health research. My objective is to show that confidentiality is broader than the concern for privacy and thus capable of capturing other relevant interests. Privacy is also considered, but only to the extent that it is useful to distinguish confidentiality and examine why the latter has been largely philosophically neglected.

The analysis is motivated by two seemingly benign, but perhaps ethically significant observations. First, there has been substantial philosophical work done on the nature of privacy and its role and importance in various contexts, yet very little scholarship has focussed on confidentiality, a closely related concept that routinely overlaps with privacy. Second, in a universal health care system like what we have in Canada, it is not unreasonable to expect that some private interests reside in the public domain, e.g. personal health information circulating within various institutions. It seems to me that much of what stirs the privacy debate in health research is not about privacy *qua* privacy, since at issue is the information that has been submitted into the public health system through clinical encounters, and widely accessed for use in research. By the time the information arrives at the desk of the observational researcher, the issue, it seems, is more about confidentiality.

Privacy may be the wider concept, but confidentiality is not narrowly confined to protecting privacy interests. The aim of this thesis is to illuminate how confidentiality is broad enough to protect other interests not captured in mere individual privacy protection, such as collective interests in privacy and trust in public institutions. I draw attention to the importance of confidentiality because it has long been philosophically neglected owing to the liberal fascination with privacy. However, as the thesis will imply, it may be confidentiality, rather than privacy, that is the pivotal concept in this discussion.

My argument presupposes a particular conception of confidentiality, one grounded in a moral framework centered on interests. Michael Yeo and Andrew Brook call this the *emergent* view of confidentiality to differentiate it from the *traditional* view claimed to be

rooted in the principles of autonomy and dignity of the individual.[9] Yeo and Brook assert that the emergent view of confidentiality is aligned with consequentialist thinking, while the traditional view corresponds to the rights-based approach of deontology. However, neither model offers a satisfactory moral framework for confidentiality in the context of observational research. The traditional model is too individualist, neglecting broader social interests; while the emergent model does not account for the important deontic principle of respect for persons. I propose a mixed model that takes both deontological and utilitarian moral considerations into account. I call this the deontic-consequentialist framework, or the *broad* view of confidentiality, since it is broad enough to capture individual and social interests. Research subjects[10] have a variety of interests that go beyond the interest in avoiding harm through disclosure. They may have interests that coincide with social objectives and thus have an interest in protecting broader social values such as charity, solidarity and trust. In chapter six I examine trust since it is fundamental to confidentiality.

The view of confidentiality that one adopts to frame the issue has implications for how we view breaches and how we assess the need for individual consent for information use in research. On a *traditional* view of confidentiality, the use and disclosure of information without consent is considered a breach. In contrast, the *emergent* view does not consider a harmless disclosure a breach, whether or not consent has been obtained.[11]

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[9] M. Yeo and A. Brook, "The Moral Framework of Confidentiality and the Electronic Panopticon" in *Confidential Relationships: Psychoanalytic, Ethical and Legal Contexts* eds. C.M Koggel et al (Amsterdam: Rodopi, 2003).

[10] In this thesis, the term 'subject' is used rather than 'participant' to reflect the reality of observational health research where individuals are studied without having given consent.

[11] Yeo and Brook, 93-94.

The *deontic-consequentialist* or *broad* view of confidentiality which I advance considers disclosure without consent a *justified* breach of confidentiality. I argue that information use and disclosure without consent is a breach, but it can be justified to the extent that the interests of subjects are protected, and persons are shown respect in the course of satisfying social objectives.

Showing respect for subjects of observational research is a challenging moral requirement. Subjects are not known to researchers, as they have no direct contact with them, and their identity is hidden through anonymity and other security measures designed to protect individual privacy. In this context, it is easy to forget that there are persons behind the data. I argue that showing respect for subjects entails recognizing them as persons and not merely as 'bits and pieces' of data to be used in research. Moreover, in acknowledging and respecting persons, we acknowledge their contribution to research, and recognize that the unconsented use and disclosure of their information for research purposes is a privilege and not an entitlement.

A *broad* conception of confidentiality depends on a culture of trust within the research enterprise. Researchers and institutions must demonstrate trustworthiness if citizens are to support and engage in that enterprise. Widespread media reports of abuses in science and medicine have precipitated a steady decline in trust, or so it seems. Philosopher Onora O'Neill argues that such claims do not mirror reality, and the public continues to place trust in civil institutions. It is important thus to repair damage to trust,

and to foster and sustain it. I suggest it can be done through openness and transparency, and in agreement with O'Neill, by acting from ethical principles that all can adopt.[12]

The utility of adopting a *broad* conception of confidentiality to frame this issue depends on whether privacy is conceived of as an individual right, and whether such a perspective informs current discussion and policy debates. Accordingly, I am tasked with demonstrating that an individualist privacy paradigm rooted in the liberal democratic tradition frames the privacy issue in health research. This framing of the issue as one of 'individual versus society' mirrors the historical private/public dichotomy, resulting in an intractable conflict. The advantage of framing the issue from the perspective of confidentiality is that it shifts the locus of attention from individualism and the emphasis on autonomy (privacy), towards relationality and the value of trust (confidentiality).

Chapter one sets the parameters for the analysis by providing a description of the research and illustrating some ways in which privacy can be threatened. I present a brief explanation of secondary uses of health information, data linkage, data mining, third-party access and commercialization of information, and restrict the analysis to the unconsented use and disclosure of personal information in observational health research.

In chapter two I present a liberal account of privacy that emphasizes individual rights and autonomy. I argue that this traditional individualist paradigm sets up the conflict between individual and societal interests which is the focus of current discussion and policy debates.

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[12] O. O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002).

Chapter three identifies informational privacy as the strand of privacy germane to the analysis and considers how violations of informational privacy not only adversely affect autonomy, but attack dignity as well. The analysis shows that violations can be experienced as abuses of trust as well as felt loss of control over one's information.

In chapter four I set out to distinguish confidentiality from privacy by identifying its conceptual elements. I argue that confidentiality is relational (in a way that privacy is not) and is characterized by vulnerability, fidelity and mutual trust. Next, I evaluate the the *traditional* and *emergent* conceptions of confidentiality as presented by Yeo and Brooke, and analyze their moral frameworks for suitability in observational health research. My analysis takes the *emergent* conception of confidentiality as relevant, but finds it deficient in failing to account for key ethical principles.

In chapter 5, I expand on the *emergent* view of confidentiality by accounting for the principle of respect for persons. I argue that this broader conception of confidentiality is able to capture wider interests, such as collective interests in privacy. In expanding the notion of interests, there is a corresponding expansion in the potential for harm, thus I review what those harms entail, giving special attention to dignitary (or symbolic) harms.

Embracing a broader conception of confidentiality depends on a culture of trust. The final chapter is an analysis of trust in research.

-- Chapter 1 --

The Perils of Observational Health Research

The expectation of privacy and confidentiality in health care presents a unique dilemma for public health interests. A great deal of observational health research[1], such as quality assurance studies, disease surveillance, and policy development depends on access to health information and other private information, often in the absence of individual consent. Although many social benefits can eventually be derived, such as improved healthcare and quality of life, it is a distinct feature of this type of research that almost none of the benefits are immediate or felt by any individual who contributes to it. Additionally, the sharing of personal health information with researchers may come at a cost to the individual in the form of stigma, discrimination, and the denial of economic and social benefits (e.g. health insurance) when disclosure of sensitive information occurs. Consequently, there is understandable concern about sacrificing individual privacy for the greater social good, when the latter is interpreted as primarily benefiting the health of others.[2] In this chapter, I provide a description of research practices that impact privacy to give some context to the analysis and illustrate some ways in which information use can threaten privacy and confidentiality. I will briefly review i) secondary uses and unspecified future uses of information; ii) data linkage; iii) data mining; iv) third-party access; and iv) commercialization of information. My objective is not to argue about the merits or disadvantages of these practices one way or the other, but

[1] Hereafter, unless otherwise specified, the term 'research' will refer specifically to 'observational health research'.

[2] A.E. Grulich and J.M. Kaldor, "Individual Privacy and Observational Health Research: Violating an Individual's Privacy to Benefit the Health of Others" (2001) 24:1 *University of NSW Law Journal* 298.

simply to illustrate some of the ways in which information use in research can be ethically challenging with respect to privacy.

What kind of research are we talking about?

It is important from the outset to distinguish health research from health care to avoid the therapeutic misconception.[3] According to the Canadian Institutes of Health Research (CIHR), "research is generally defined as a systematic investigation designed to develop or establish principles, facts or generalizable knowledge. The goals of health research, in the context of CIHR's mandate, are to create new knowledge and to enable its translation into improved health for Canadians, more effective health services and products, and a strengthened health care system."[4] Health care, broadly construed, refers to the provision of services that help individuals achieve and maintain well-being during the different stages of the human life cycle.[5] The crucial difference lies in the extent of the benefits that individuals accrue. While individuals benefit directly from receiving health care, they may not receive any individual benefit from participating in research. It is a distinct feature of research that benefits may not be felt immediately or experienced by any one participant. Generally, the benefits of research materialize and accumulate over time, thus it is society as a whole that reaps the benefits. This is particularly true of

[3] The 'therapeutic misconception' is the phenomenon whereby patients confuse the goals of research with the goals of treatment, believing that enrolling in a research study (e.g. a clinical trial) will result in a therapeutic benefit for themselves. For a detailed explanation see C.W. Lidz's, "The Therapeutic Misconception and Our Models of Competency and Informed Consent" (2006) 24:4 *Behavioural Science and Law* 535.

[4] Canadian Institutes of Health Research (CIHR). *Guidelines for Protecting Privacy and Confidentiality in the Design, Conduct and Evaluation of Health Research: Best Practices,* Consultation Draft (Ottawa: Public Works and Government Services Canada, 2004).

[5] Health care includes medical examinations, evaluations, diagnoses, treatment, aids, and a host of related *therapeutic* services.

the type of research which is the subject of this analysis. Here we are talking about research that uses personal information derived from health records and other sources, including biological tissues, and the focus will be on information used without the knowledge or consent of the individual to whom it pertains.[6]

There is disagreement among scholars about what constitutes personal information. For our purposes we shall employ CIHR's definition of personal information: any information that: i) identifies an individual (e.g. name, street address); or ii) could potentially identify a person by reasonably foreseeable means if information contained in the record is combined, or information in the records is combined with other available information. CIHR's definition is consistent with the European Union's Directive of 1995 which governs data protection legislation in many European countries and which is influential in privacy discourse. The Directive is somewhat more explicit than CIHR's definition; it states:

> " 'personal data' shall mean any information relating to an identified or identifiable natural person ('data subject'); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity."[7]

Identifiability has in several instances become the test of what counts as 'personal information'. In his influential report for The Nuffield Trust, William Lowrance maintains that "if data aren't identifiable they aren't 'personal', and a variety of rights, obligations, and sanctions that apply to personal data are not relevant. *Research on*

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[6] Consented or known uses are evidently pertinent with respect to privacy in research and involve similar security concerns, but I will focus the analysis on unconsented uses of information since the latter is perceived as more contentious and of greater threat to individual privacy.

[7] Article 2(a) of Directive 95/46/EC of the European Parliament.

anonymised data is just research on cases, not persons [original emphasis][8]. The United States Office for Human Research Protections (OHRP) takes a similar view asserting that human subject research is limited to *living* individuals from whom data is i) directly obtained through intervention or interaction, or ii) identifiable private information – where the latter must be "**individually identifiable** (i.e., the identity of the subject is or may be readily ascertained by the investigator or associated with the information) in order for obtaining the information to constitute research involving human subjects (bolding added for emphasis)."[9] Important ethical implications of the OHRP's stance are that it fails to explicitly acknowledge the identifiability of *groups* or *communities* as relevant for the identification of individuals, and it does not recognize deceased individuals as 'human subjects'. Ontario's *Personal Health Information Protection Act* (PHIPA) applies to the information of deceased individuals (so long as death has not occurred more than fifty years ago), so it does recognize the deceased as having interests. However, PHIPA only applies to information about an individual if it can 'reasonably' be used to identify the individual.[10] This is more stringent than the OHRP's test of identifiability as what can be 'readily ascertained'; however, what is 'reasonably' identifiable is an open question, I suppose. The office of the Ontario Information Privacy Commissioner (IPC) offers guidance on how to interpret the legislation, but it does not speak specifically to what can

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[8] W. W. Lowrance, *Learning from Experience: Privacy and the Secondary Use of Data in Health Research* (London: The Nuffield Trust, 2002), p. 27.

[9] United States Department of Health and Human Services (HHS), Office of Human Research Protections (OHRP), *Guidance on Research Involving Coded Private Information or Biological Specimens,* 2004. Available: http://www.hhs.gov/ohrp/humansubjects/guidance/cdebiol.htm

[10] Personal Health Information Protection Act, 2004. [S.O. 2004, Chapter 3 Schedule A]. Available: http://www/elaws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm#BK8

be considered reasonably identifiable.[11] I do not share these perspectives on identifiability. My own view is that personal information is any information which pertains to a person, so it matters not whether that information is in anonymised form. Anyone is potentially identifiable given the right set of circumstances.

Personal information is collected from a variety of sources, including, but not limited to: physician and hospital records, government records (e.g. birth and death registrations), and from the private sector. It is used for conducting epidemiological studies, quality assurance studies, disease surveillance, and a host of other research initiatives centered on population health. As the Tri-Council Policy Statement (TCPS) notes, "without access to personal information, it would be difficult, if not impossible, to conduct important societal research in such fields as epidemiology, history, genetics and politics, which has led to major advances in knowledge and to an improved quality of life."[12]

The information collected may be amassed and kept in large data repositories, such as institutional databases[13], clinical registries, and in the case of tissue samples, biobanks. These are broad categories to describe the infrastructure that holds the information; the size and scope of these repositories vary considerably. They can range from formalized and well regulated structures, such as the Canadian Institute for Health Information

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[11] Office of the Information and Privacy Commissioner / Ontario. *A Guide to the Personal Health Information Protection Act* (2004). Available: www.ipc.on.ca/images/Resources/hguide-e.pdf

[12] Tri-Council Policy Statement (TCPS). *Ethical Conduct for Research Involving Humans*, Section 3. (Ottawa: Public Works and Government Services Canada, 1998).

[13] I do not distinguish between the terms 'database' and 'databank'. In this document they are used interchangeably to refer to a formally structured dataset organized in such a way that it can be accessed by users locally and remotely. A databank may be composed of one or more databases; conversely, a database may include one or more databanks.

(CIHI), or they may be smaller, more informal collections held by individual researchers or institutions, such as outpatient datasets or the specimens kept in a pathology lab.[14] Moreover, they may be clinical in nature, i.e. those initially assembled in the course of routine patient care, or they may be research-oriented, prospectively created with the intent to be used in research. Of the latter kind, "genetic databases are becoming increasingly common as a means of determining the relationship between lifestyle, environmental exposures and genetic diseases." [15] One of the important ways in which research databases differ from clinical datasets is that consent is obtained from patients for inclusion in the database. In such cases patients are aware that they are subjects of research, but they may not be apprised of the individual studies that emanate from the database, thus they have little knowledge about the details of the research itself.[16] For example, they may not know how often the database is accessed, who has access to it, and what specific research questions are asked.

Technology facilitates the collection, storage, use and dissemination of information. Thanks to the computer and internet, vast quantities of information may be accessed and transmitted anywhere around the world almost instantaneously. Electronic health records (EHRs) are becoming commonplace, and there are plans to augment and integrate these into the Canadian healthcare system. Canada Health Infoway is an independent non-

[14] An informal assessment conducted at the Hamilton Health Sciences Corporation (HHSC) discovered that it held over 8000 patient databases. Some were quite small, having less than 100 subjects, while most had over hundreds and even thousands of subjects. It was unclear whether these were consent-based. [As reported by Dr. Suzete Salama, HHS/FHS REB member, at the McMaster Bioethics Interest Group (BIG), Spring 2005]. For a comprehensive table of the variety of research databases held in diverse settings consult the CIHR's *Best Practices for Protecting Privacy in Health Research,* 2005.

[15] T. Caulfield et al., "DNA databanks and consent: A suggested policy option involving an authorization model" (2003) 4 *BMC Medical Ethics* 1.

[16] Patients may issue a 'broad consent' for inclusion in a research database on condition that a Research Ethics Board approves individual research studies that make use of it.

profit organization working with the public sector to accelerate the implementation of electronic health information systems in Canada. Their goal is "to have an interoperable EHR in place across 50 per cent of Canada (by population) by the end of 2009."[17] Moving from a paper-based system to an electronic health record has clear advantages for both clinical and research applications. Clinicians have instantaneous access to a patient's lifetime health history which can promote efficiency in clinical decision-making, diagnoses and treatment; while researchers have a rich data resource they can easily tap into. This move towards electronic data use is consistent with what CIHR describes as the current 'research landscape'. That landscape consists of multidisciplinary networks of researchers across provinces and across countries sharing research platforms and information.[18] Electronic data facilitates this type of collaboration precisely because it is so easy to transmit and manipulate. A trans-border collaboration of the size and scope of the international Human Genome Project (HGP) perhaps would never have materialized if not for the advent of electronic data exchange.

1.2 Ethically Questionable Methods?

Notwithstanding the positive ways in which information technology has revolutionized health research, there are ethical concerns about how the data is accessed and used. With respect to privacy and confidentiality, ethicists are increasingly worried about: i) secondary uses and/or unspecified future uses of the information; ii) linkage with

[17] Canada Health Infoway. *Who We Are* (2006). Available at http://www.infoway-inforoute.ca/en/WhoWeAre/Overview.aspx.

[18] CIHR, *Guidelines for Protecting Privacy and Confidentiality in the Design, Conduct and Evaluation of Health Research: Best Practices* Consultation Draft, April 2004, p. 8.

other datasets; iii) data mining; iv) access by third parties; and v) commercial or for-profit uses of the information. The concerns relate to how the infringement on privacy and confidentiality diminish the autonomy of individuals and can result in psycho-social harms for both individuals and communities when sensitive disclosures take place.

1.2.1 Secondary Uses and Unspecified Future Uses of Information

'Secondary uses of information' refers to uses which were not intended or foreseen when the information was initially collected. It is not uncommon for information that is gathered in the course of diagnosis and treatment to become a source of research data. For example, a patient consents to having their blood pressure taken as part of routine physical check-ups. In addition to being recorded in the patient's health record, this data may also be included in an in-house registry that tracks the number of patients presenting with hypertension. The in-house registry is maintained for quality assurance purposes, thus no additional consent is needed from the patient to add her data to it. However, at a later time, this information may be used for research, e.g. a study that examines how many patients diagnosed with hypertension were also admitted to hospital for coronary complications. This would constitute a secondary use of that information, but it is permissible without individual consent if the study is undertaken under the auspices of 'quality control' or 'education'. At present a substantial amount of research conducted electronically in databases, such as public health surveillance, studies of disease patterns of occurrence, determinants, and evaluation of healthcare interventions

and services, relies on data that was not specifically collected for research.[19] Furthermore, it is thought that "the scale of secondary use of information from the medical record will increase substantially as the electronic health record becomes more pervasive."[20]

The practice of secondary uses can also occur with human tissues. Tissue specimens that are initially collected for diagnostic purposes may be retained in the laboratory and used later for research. Often it is not possible to obtain consent from the tissue donor for this new intended use of the 'left-over' sample. As noted in article 3.4 of the TCPS, "it may be impossible, difficult, or economically unfeasible to contact all subjects in a study group to obtain informed consent. This can occur when the group is large or its members are deceased, geographically dispersed or difficult to track."[21] Thus researchers and ethicists struggle with the question of whether it is ethically permissible to use the tissue without consent. Even when it is possible to obtain consent, it may not be desirable from a research perspective. Offering subjects a choice between consent and nonconsent may introduce significant bias into a study.[22] These challenges are not limited to tissues –they also apply to data.

When consent is sought upfront, such as in the case of prospectively collected research data, there may still be questions around 'secondary uses', particularly when it is unclear whether all intended uses were made explicit in the consent process. Someone

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[19] Lowrance, p.1.

[20] D.J. Willison et al, "Alternatives to Project-specific Consent for Access to Personal Information for Health Research: What is the Opinion of the Canadian Public?" (2007) 14:6 *Journal of the American Informatics Association,* p. 707.

[21] TCPS, *Ethical Conduct for Research Involving Humans*, article 3.4.

[22] J.S. Horner, "Research, ethics and privacy: the limits of knowledge" (1998) 112 *Public Health*, p 218.

may consent to inclusion in a database of gastric disorders, but could potentially object to the use of this information to ascertain patterns of alcoholism associated with disintegration of the stomach lining.

The question of 'future-uses' of information is equally problematic, if not more contentious. When information is prospectively collected for inclusion in a databank there is no way to imagine all the possible eventual uses that will be put to it. The subject is faced with increased disclosure risk, and the possibility of contributing to research that she objects to, or which might later come to stigmatize her. This raises doubts about the validity of informed consent. Caulfield et al. have argued that conventional forms of informed consent are woefully inadequate to address this challenge posed by genetic databanks. They systematically reject proposals for open-ended 'blanket consents' since these are "far too general" and "do not allow patients to meaningfully act on their continuing interest in their health information".[23]

1.2.2 Data Linkage

Another research practice that can threaten personal privacy is data linkage. There is tremendous interest in linking various data sources to yield a richer and more detailed 'account' of the subject of interest. Roos et al report that "record linkage is now being used routinely by a number of Canadian and Australian research centres," and that "…linkage is critical for expanding population-based research beyond its historical

[23] Caulfield et al., p. 4. Elaine Gibson argues that individuals may have an ongoing privacy interest in anonymised information; see "Is There a Privacy Interest in Anonymised Personal Health Information?" (2003) 97 *Health Law Journal.*

'home' with health care information to additional topics more generally connected with well being."[24] This is reflective of a trend that is expanding the sphere of health research to include social research objectives. Consider the Population Health Research Unit (PHRU) at Dalhousie University which has assembled an incredible network of linked databases that provide "unparalleled opportunities for research in the health and social sciences"[25] . According to PHRU,

> "In a time of health care reform, spending constraints and an expanding world of therapies and technologies, the need for efficient and effective support services for population-based research has never been greater. To facilitate the growth of research in these areas, the Province of Nova Scotia has supplied PHRU with complete Medicare, Pharmacare and Hospital files suitable for research purposes. The Unit has also been supplied with Workers Compensation records and has access to a variety of other data sources including clinical databases and large scale population surveys."[26]

We can imagine that if the other data sources include social assistance data, police records, or the child protective services database, PHRU researchers can entertain an interesting mix of research questions. For example, one might be interested in finding out what proportion of babies born with congenital heart defects are born to mothers on social assistance that have a past criminal record. While one could certainly justify a connection between maternal-foetal health and social assistance given what we know about poverty and the social determinants of health[27], an association between maternal-foetal health and

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[24] L.L. Roos et al "From health research to social research: Privacy, methods, approaches" (2006) 66 *Social Science and Medicine* 118.

[25] Population Health Research Unit (PHRU), Dalhousie University. Available: http://www.phru.dal.ca/about/

[26] Ibid.

[27] Empirical evidence suggests there is a causal relationship between low socioeconomic status and poor health outcomes. See N. Spencer, "Socioeconomic determinants of health related quality of life in

past criminal behaviour seems gratuitous. A study of this nature is likely to be of little social value and it stigmatizes the mothers and perpetuates stereotypes about the poor. Yet the ability to link the various datasets makes research of this nature possible. To be clear, it is not data linkage per se that is objectionable. Although, as William Lowrance observes, "linking can be vaguely troubling –vaguely, in that it can be hard to say precisely why it is troubling."[28] My point is simply that data linkage opens the possibility for new and inappropriate research pursuits that can be harmful to individuals and groups, thus we need to be vigilant. Lowrance concludes that, "linked-up material does amount to a fuller description than the bits unlinked, and thus may present higher potential for abuse."[29]

1.2.3 Data Mining

We might ask how researchers are inclined to ask those sorts of questions to begin with, bringing us to the third issue of concern – data mining. Data mining is part of a process known as knowledge discovery in databases (KDD), which is "a computerized technique used to discover patterns in data and to analyze and interpret that data into useful knowledge."[30] Data mining is a particularly useful tool in genomic research, enabling researchers to sift through the DNA of large populations to identify underlying genetic determinants of disease. A data mining method known as 'the shotgun method'

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childhood and adolescence: results from a European study" (2006) 32:5 *Child Care Health Development* 603-4.

[28] Lowrance, p. 46.

[29] Ibid.

[30] H. T. Tavani, "Genomic research and data-mining technology: Implications for personal privacy and informed consent" (2004) 6 *Ethics and Information Technology*, p. 21.

was instrumental in the completion of the initial phase of the HGP.[31] One way in which data mining technology has transformed research is the way in which research questions are generated. Tavani notes that, "in the past, epidemiological researchers tried to find patterns and relationships in data by forming hypotheses."[32] For example, a physician might observe that several of his patients being treated for thrombosis have large hands. Subsequently, the physician might formulate a hypothesis about the relationship between thrombosis and large hands before embarking on a study to determine the connection.[33] However, with data-mining technology no initial hypothesis of disease is necessary. This is in part because data-mining is not restricted to causal relationships; it considers a wider range of possible relations and can disclose previously undetected patterns. Thus data-mining techniques might reveal an association between mothers of children born with congenital heart defects that are recipients of welfare and have a prior arrest record. There may not be a causal correlation between all three factors, but there need not be. What is so insidious about data-mining is that it presents both causal and non-causal correlations on the same footing – as newly discovered associations.[34] This capacity to suggest previously unseen 'new facts' is ethically problematic. Consider the example of group profiling that Tavani offers as an illustration. Group profiling entails the assignment of individuals that bear the relevant properties or characteristics to a group defined by those same properties or characteristics. For example, I may at once be assigned to the group of females, parents, graduate students, and so forth. According to

[31] Ibid.
[32] Ibid.
[33] Ibid.
[34] Ibid, p. 22.

Tavani, most of the time people are not surprised to find themselves assigned to these groups.[35] However, data-mining tools permit the discovery of so-called 'new facts' that create unusual and controversial groups.

> "[A] data-mining application might reveal the existence of a group of people who both drive red cars and have colon cancer. The owner of a red car may be very surprised –perhaps even shocked –to learn this new fact about him –viz. that he has been assigned to a group of individuals likely to have or to contract colon cancer merely because of a statistical correlation that seems arbitrary."[36]

Consider what the implication for this group might be in terms of health insurance: we might expect owners of red cars to unjustly pay higher premiums. Clearly, certain data-mining techniques raise concerns about privacy and justice. Moreover, there are obvious epistemological limitations that need to be addressed. As in the case of data linkage, data mining itself is not inherently problematic. However, the technology does present ethical challenges that we should be prepared to confront.

1.2.4 Third Party Access

Third party access to personal information is a principal concern not only of patients and subjects, but of the data custodians that have the responsibility to safeguard the information. Third party users might include employers, insurance companies, government agencies, the private sector and others not directly involved in the research, but having an interest in the data. We can distinguish third party access in terms of authorized and unauthorized disclosures. There is good reason to worry about

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[35] Ibid.
[36] Ibid.

unauthorized disclosure of personal information given the dire consequences that can ensue. Consider the following:

> "[A] database created by the state of Maryland to keep the medical records of all its residents for cost containment purposes was used illegally by state employees to sell confidential information on Medicaid recipients to sales representatives of health maintenance organizations (HMOs), and it was also used by a banker to call in the loans of those bank customers whom he thus discovered had cancer."[37]

> "[A] state health department worker using state computers compiled a list of 4,000 people who tested positive for HIV and forwarded it to a local health department and two newspapers…"[38]

Despite the magnitude of these abuses, it is not the mischief of unethical employees that we should worry about, for these are rare and isolated incidents. The immediate concern lies with *authorized* disclosures to third parties –violations that are legally permitted, but ethically suspect. Judith Wagner DeCew observes that "it is widely recognized that the risks of fraud and abuse of individual medical information comes not from outside hackers, but mainly from those described as 'authorized' users."[39] Indeed, "most violations of privacy of medical records are the result of the legally sanctioned –or at least tolerated –unconcealed , systematic flow of medical information from the orbit of the physician-patient-health insurer and health management corporation to other non-health care parties, including employers, marketers, and the press."[40] An employer might request health information as a safety precaution if an employee's duties demand a certain level of fitness, as when one is entrusted with the operation of machinery or heavy equipment. But having sensitive health information disclosed to one's employer may

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[37] A. Etzioni, *The Limits of Privacy* (New York: Basic Books, 1999) p. 140.
[38] Ibid, p. 141.
[39] J.W. DeCew, "Privacy and policy for genetic research" (2004) 6 *Ethics and Information Technology*, p. 7.
[40] Etzioni, p. 144.

jeopardize employment or advancement opportunities. In similar fashion, one may be denied insurance benefits by an insurer on the basis of an 'unsatisfactory' health report. Additionally, one's employability and insurability prospects may diminish when genetic information is disclosed. If a genetic test identifies a propensity for a particular disorder, it may come to be interpreted as a likely or definitive eventual affliction, resulting in discrimination on the basis of one's genes.[41] A recent study at Johns Hopkins University found that individuals with expressed genetic conditions are twice as likely to be denied health insurance, than individuals with other chronic illnesses.[42]

1.2.5 Commercialization of Information

Directly related to third party access is the issue of commercialization or for-profit uses of health information. The commodification of human beings and their parts and products has been an issue of ongoing concern among bioethicists. For years the discussion has centered on the sale of tissues, e.g.gametes, and reproductive practices such as surrogate motherhood. However, the issue of commodification has expanded to include the commercialization of health information, particularly genetic information, as private sector genetic databanks continue to proliferate. As well, private-public partnerships are quickly becoming commonplace. Bauer et al claim that "tissue banking research increasingly is conducted in partnership between the for-profit and not-for-profit

[41] V. Launis. "Solidarity, Genetic Discrimination, and Insurance: A Defense of Weak Genetic Exceptionalism" (2003) 29:1 *Social Theory and Practice* p.88.

[42] "Individuals with genetic conditions twice as likely to report health insurance denial". Available: http://www.jhsph.edu/publichealthnews/press_releases/2007/kass_genetic_testing.html. The study examined the health insurance experiences of individuals with genetic conditions versus those of individuals with serious chronic disease. The study participants had sickle cell disease, cystic fibrosis, breast cancer, colon cancer, diabetes or HIV.

spheres"[43] and much of the non-profit sector is supported by pharmaceutical and biotech industries that fund academic research.[44] One prominent example of this partnering is the case of deCODE Genetics Inc., a private company that was awarded exclusive rights by the Icelandic government to operate the nation's health records databases for 12 years. As a result of this exclusivity, "researchers who are not affiliated with deCODE are required to pay for the use of medical information that was once freely available to them."[45] The databank is, according to some critics, an example of where "public and private interests have been unhappily mixed"[46] since the issue of commercialization is only one among many ethical issues facing deCODE Genetics. Yet this trend towards commercialization is perhaps unavoidable, given that the public and private sectors have common research interests. Even academic research which traditionally has been viewed as impervious to the temptation of commercialization has become susceptible as more university-based research is now funded by both public and private sources,[47] and incentives are offered to develop commercially viable research.[48]

Some theorists, however, view these alliances as a positive turn. Bauer et al assert that "perhaps the most important benefit associated with the commercialization of human tissue comes from the successful interchange between the two spheres, toward a more

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[43] K. Bauer et al, "Ethical Issues in Tissue Banking For Research: A Brief Review of Existing Organizational Policies" (2004) 25*Theoretical Medicine*, p. 113.

[44] Ibid.

[45] Tavani, p. 17.

[46] V. Árnason, "Coding and Consent: Moral Challenges of the Database Project in Iceland" (2004) 18:1 *Bioethics*, p.40.

[47] CIHR, *Best Practices* Consultation Draft, 2004.

[48] Consider Aggregate Therapeutics Inc. recent deal with the Canadian Stem Cell Network. Aggregate Therapeutics, a development stage regenerative medicine company, has an exclusive first right to commercialize technologies from the laboratories of 37 leading Canadian scientists, most of them university-based academics. Available http://www.aggregatetx.com/.

efficient transmission of knowledge from academic-based tissue banks to industry, facilitating the development and delivery of medical products to the public."[49] But who can forget the poignant story of John Moore whose white blood cells were immortalized in the 'Mo' cell line, an endeavour that was estimated at a worth of $3.01 billion. Moore never saw one cent of it, although the physician who treated him for hairy cell leukemia and who subsequently used his cancer cells for research without consent managed to negotiate lucrative agreements with two private companies.[50] In Japan, a court auctioned off a human cell collection from a private tissue bank gone bankrupt, despite protests from the tissue donors.[51] Fear of commercialization of personal information and bodily tissues is now cited as a deterrent to participating in research.[52] The issue of commercialization exacerbates the issue of third-party access to personal information, not only because it widens the circle of disclosure, but arguably because it has the potential to commodify the persons whose information is used.

Researchers claim that "advances in the knowledge of the aetiology, clinical characteristics, prognosis and treatment of diseases would be seriously impaired if investigators were unable to consult personal information contained in medical records or the archives of biological samples."[53] Moreover, there is clear evidence that continued investment in health research plays a crucial role in supporting evidence-based medicine,

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[49] Bauer et al, p. 128.

[50] R. F. Weir and R.S. Olick, *The Stored Tissue Issue* (New York: Oxford University Press, 2004), p. 157.

[51] S.O. Hansson, "The Ethics of Biobanks" (2004) 13 *Cambridge Quarterly of Healthcare Ethics,* p. 323.

[52] Human Genetics Commission, *Inside Information: Balancing interests in the use of personal genetic data,* (London: Department of Health, 2002).

[53] E. Regidor, "The use of personal data from medical records and biological materials: ethical perspectives and the basis for legal restrictions in health research" (2004) 59 *Social Science and Medicine,* p. 1975.

leading to improved quality of care.[54] Thus society benefits tremendously from health research. Nevertheless these benefits do not come without a cost. In the conduct of research, personal information is susceptible to secondary and unspecified uses, linkage with other data, data mining, access by third-parties, and commercialization. On their own these practices raise a variety of ethical and epistemological concerns. I shall restrict my analysis to concerns related to the privacy and confidentiality of information.

[54] CIHR, *Best Practices* Consultation Draft, 2004, p. 5.

-- Chapter 2 --

Privacy: The Master Concept

Confidentiality and privacy are closely related concepts and some attention to the latter is thus warranted. In the introduction we stated that privacy would be considered secondarily, to the extent that it is useful for distinguishing confidentiality and for understanding the apparent conflict between individual privacy and health research. We also noted that reframing the privacy issue in health research as one of confidentiality could be useful if privacy in this context was conceived of as an individual good, since this conception contributes to the tension between individual interests and societal interests which is at the heart of the conflict. Thus the aim of this chapter is to provide an overview of a common liberal conception of privacy, and to illustrate how this is the dominant paradigm informing the privacy issue and related policy questions in health research concerned with information use.

The liberal conception of privacy considered here emphasizes individual rights and autonomy and strongly favors individual consent for use of information.[1] Both autonomy and consent are dominant concepts in bioethics discourse. This tendency towards individualism has the unfortunate result of framing privacy "as an interest of selfish individuals"[2] when contrasted against the societal interest in health research.

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[1] We should acknowledge that there are various strands of liberalism and not all are representative of the individualistic atomism that is often presented in the bioethics literature engaging in the privacy-versus-health research discourse. Joseph Raz gives a more nuanced account of liberalism in *The Morality of Freedom* (Oxford: Oxford University Press, 1988) and in, *Is There a Right of Freedom of Expression?* (Cambridge: Cambridge University Press, 2005).

[2] D. Willison, "Privacy and the secondary use of data for health research: experience in Canada and suggested directions forward" (2003) 8:1 *Journal of Health Services Research and Policy*, p. 19.

Additionally, this framing of conflicting interests requires the adoption of a 'balancing approach' in policy that demands ongoing evaluation and where one side is bound to come out dissatisfied.

From a philosophical perspective, the emphasis on privacy has left an important concept such as confidentiality largely ignored in this discussion. Privacy enjoys the theoretical limelight. It is a notoriously difficult concept to define and there is little agreement about its nature, value and scope. One might expect that considerable attention would thus be devoted to its exploration and understanding. In contrast, confidentiality is understood to be a fairly well established principle, firmly entrenched in legal doctrine as a fiduciary duty in specified relationships. It has received scant philosophical attention and remains the residual concept of analysis where privacy issues are considered in the context of observational research.

In what follows, I present what I see as the two pivotal reasons for the tendency to focus on individual privacy where information use in research is concerned: i) its place in the liberal democratic tradition and ii) its connection to autonomy, where the latter is also a privileged concept in bioethics. Next, our analysis shows that informed consent, which is thought to be the best way to protect autonomy, can be limited in several ways and thus sometimes inadequate for securing individual autonomy. In the last section I demonstrate that the individualist conception of privacy is the dominant paradigm informing discussion and related policy questions.

2.1 The Complexity of Privacy

It is customary for commentators on privacy to preface their discussion with some remarks that suggest the enormous complexity of the subject. I will borrow mine from Judith Jarvis Thomson's seminal paper "The Right to Privacy". Thomson writes, "Perhaps the most striking thing about the right to privacy is that nobody seems to have any very clear idea what it is."[3] It has been well over 30 years since Thomson issued her claim and the lack of clarity surrounding the nature of privacy persists, having grown multifarious and divisive, and acquiring neologisms along the way as new contexts shape the contours of the 'privacy problem'. We now speak of spatial privacy, decisional privacy, physical privacy, informational privacy, genetic privacy, and even neuroprivacy. Extant definitions of privacy are as many as they are complex. Indeed much of the perplexity surrounding privacy discourse has to do with the often antagonistic definitions which abound. Privacy has been loosely defined as 'the right to be let alone', 'the right to control information about oneself' and the 'right to make decisions free from public intrusion'. Many scholars describe privacy as a value rather than a right, and some are suspicious of its value and significance altogether. As theorist Jeff Weintraub notes, "the enormous bodies of discourse that use 'public' and 'private' as organizing categories are not always informed by careful consideration of the meanings and implications of the concepts themselves."[4] Various theoretical positions come to bear on privacy's multiple understandings; however, there is general concordance that liberalism is the dominant

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[3] J. J. Thomson, "The Right to Privacy" (1975) 4 *Philosophy and Public Affairs* 295.

[4] J. Weintraub and K. Kumar, eds. *Public and Private in Thought and Practice: Perspectives on a Grand Dichotomy* (Chicago: The University of Chicago Press, 1997), p. xii.

framework informing contemporary notions of privacy and the bulk of related law and policy.[5]

2.2 Historical Conditioning and the Privacy Paradigm

> *Liberalism can be understood in historical terms...The specific contribution of the liberal tradition to political morality has always been its insistence on the respect due to individual liberty.*[6]
>
> -- Joseph Raz

Liberalism defends privacy as an individual right necessary for autonomy and human flourishing. It advocates strongly on behalf of individual protection against interference from the state[7], thus it reflects the historical separation between the private and public spheres that can be traced back to the Ancient Greeks. Aristotle distinguished between the public sphere of political life, the *polis,* and the private sphere of domestic life, the *oikos*.[8] Later, both Locke and Mill adopt the private/public distinction in their treatises on the nature of the individual and governmental authority. In his *Second Treatise on Government,* Locke asserts that in a state of nature all assets are held in common and are thus public, however, the individual retains possession over himself, his body, and that with which he mixes his labour becomes his own private property.[9]

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[5] See W. Lowrance's *Learning from Experience: Privacy and the Secondary Use of Data in Health Research* (London: The Nuffield Trust, 2002) and A. Etzioni, *The Limits of Privacy* (New York: Basic Books, 1999). See also P. Regan's *Legislating Privacy: Technology, Social Values, and Public Policy* (Chapel Hill: The University of North Carolina Press, 1995).

[6] J. Raz, *The Morality of Freedom* (Oxford: Oxford University Press, 1988), p. 2.

[7] J.S. Mill, *On Liberty* (Indianapolis: Hackett Publishing Company, Inc., 1978).

[8] J. Swanson, *The Public and the Private in Aristotle's Political Philosophy* (Ithaca: Cornell University Press, 1992). Swanson offers a different interpretation than the common view, arguing that the private in Aristotle's philosophy is not subordinate to the public but rather necessary for it.

[9] J. Locke, *Second Treatise on Government.* Ed. C.B. MacPherson (Indianapolis: Hackett Publishing Company, Inc., 1980).

Mill argues against the 'tyranny of the majority', restricting political authority to matters concerning the well-being of others. In respect of the individual, Mill claims that,

> "[T]he only part of the conduct of anyone for which he is amenable to society is that which concerns others. In the part which merely concerns himself, over his own body and mind, the individual is sovereign."[10]

The liberal ideal of retaining sovereignty over oneself in a private sphere distinct from the public realm emerges as a right of privacy in 1890, when Warren and Brandeis introduce the 'right to be let alone'.[11] According to Warren and Brandeis, a right to be free from public intrusion is indispensable for maintaining the integrity and dignity of the individual.[12] Contemporary theories of privacy that emerge in the 20th century import some aspect of Warren and Brandeis's claim. Most theories are centered on limiting or controlling the access of others,[13] preserving the dignity of the individual,[14] protecting intimacy,[15] and enabling the development of interpersonal relationships.[16] What is held in common in all of the theories is that they affirm a clear distinction between the private and the public, and consider the preservation of individual autonomy as fundamental.

But not all theories espouse liberalism, accept the private/public dichotomy, or subscribe to the liberal notion of autonomy described above.[17] Feminist theorists in

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[10] Mill, *On Liberty,* p. 9.

[11] S.D. Warren and L. Brandeis, "The Right to Privacy" (1890) 4:5 *Harvard Law Review.*

[12] Ibid.

[13] R. Gavison, "Privacy and the Limits of the Law" (1980) 89 *Yale Law Journal* 421; and, A. Allen, *Uneasy Access* (New Jersey: Rowman and Littlefield Publishers, 1988); and, B. Rössler, *The Value of Privacy* (Oxford: Polity, 2004).

[14] E Bloustein, "Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser" (1964) 39 *New York University Law Review* 962; and, T. Nagel, *Concealment and Exposure* (New York: Oxford University Press, 2002).

[15] R. Gerstein, "Intimacy and Privacy" (1978) 89 *Ethics* 76.

[16] F. D. Schoeman, *Privacy and Social Freedom* (New York: Cambridge University Press, 1992).

[17] For an excellent account of 'relational' autonomy see S. Sherwin's (ed.), *The Politics of Women's Health: Exploring Agency and Autonomy* (Philadelphia: Temple University Press, 1998).

particular have been critical of the role of privacy in concealing the abuse, domination, and oppression of women and other vulnerable members of society.[18] From this perspective, privacy enables exploitation and prevents women from actively participating in political life. Many feminists would thus like to collapse the distinction and bring the private into the public to garner legitimacy for the home, and empower those obscured in the shadows of privacy. Others like Anita Allen and Patricia Boling adopt a more moderate stance, arguing that dispensing with privacy altogether is untenable, since, as Boling notes, "some matters rooted in intimate life need to be hidden and protected from public exposure rather than politicized. Often the personal is *not* political, is not public, and is not anyone's business."[19] [original emphasis]

Communitarians also reject this individualist liberal conception of privacy, concerned that communal interests are jeopardized when subordinated to individual interests. As one social theorist claims, "…society advances or regresses as individuals choose either a private existence or a life of public coexistence….privacy begets conservatism, retrogression, and stagnation."[20] Etzioni laments that, "the tendency to allow privacy considerations to take precedence over concerns for public safety and health is not accidental"[21], but reflective of deeply embedded beliefs about privacy fuelled by a traditional liberal conception. Etzioni claims this conception is outdated and

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[18] P. Boling, *Privacy and The Politics of Intimate Life* (Ithaca: Cornell University Press, 1996), p.xi. See also A. Allen, *Uneasy Access: Privacy for Women in a Free Society* (New Jersey: Rowman & Littlefield, 1988), and C. Armstrong and J. Squires, "Beyond the Public/Private Dichotomy: Relational Space and Sexual Inequalities" (2002) 1 *Contemporary Political Theory* 261.

[19] Boling, p. xi

[20] R.F. Hixson, *Privacy in a Public Society: Human Rights in Conflict* (New York: Oxford University Press, 1987), p. xiii.

[21] A. Etzioni, *The Limits of Privacy* (New York: Perseus Books Group, 1999), p. 187.

no longer reflects current conditions, which are the expansion of a pluralist society, and more importantly, a polity going astray in its endeavour to balance two fundamental, but conflicting interests.[22] Accordingly, he advocates reformulating privacy as a social good. To be clear, Etzioni does not devalue the importance of individual privacy, he simply rejects any *a priori* privileging of the right to privacy.[23] Priscilla Regan is similarly critical of an individualist privacy paradigm and also advances a social conception of privacy. Regan argues that, "privacy serves not just individual interests but also common, public, and collective interests. A recognition of the social importance of privacy will change the terms of the policy debate….".[24] In sum, a social conception of privacy does not dispense with the individual right to privacy, it simply affirms that: privacy is a *common* value in that everyone values some degree of privacy; it is a *public* value, essential to a democratic political system; and it is a *collective* value in contemporary society, where as Regan notes, "technology and market forces are making it hard for any one person to have privacy without all persons having a similar minimum level of privacy."[25] Proponents of a social conception of privacy simply want to eliminate the emphasis on individualism to downplay what appears to be a conflict between individual and societal interests.

The dissenting voices of feminism, communitarianism, and other social philosophies challenge the liberal privacy ideal and the values of individualism, power

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[22] Ibid, p. 5.
[23] Ibid, p.188.
[24] P. Regan, *Legislating Privacy: Technology, Social Values, and Public Policy* (Chapel Hill: The University of North Carolina Press, 1995)., p. xiv.
[25] Ibid, p. 213.

and authority it presupposes. But the tide has not turned. Contemporary privacy norms are still very much dominated by this particular liberal conception.

2.3 Privacy and Autonomy

> *The justification of the right to privacy under a democratic government is its role in fostering individual autonomy.*[26]
>
> --Vincent J. Samar

Within the liberal tradition, privacy is intimately connected with individual autonomy. Autonomy, like privacy, is a protean concept. It usually refers to one's capacity for self-determination, to make free and unencumbered choices regarding one's life, to live as one so chooses; further, it "is generally depicted as a capacity or trait that individuals may have to a greater or lesser degree, which they will manifest by acting independently, in the right and appropriate way."[27] Some theorists view privacy as essential for autonomy, as a necessary condition "to be recognized by others as capable of independent decision making and worthy of being left alone".[28] Autonomy is sometimes used as the justification of a right of privacy.[29] Others like Joel Feinberg see privacy as an element of autonomy. He claims, "my right to determine by my own choice what enters my experience is one of the various things meant by the 'right of privacy', and so interpreted that right is one of the elements of my personal autonomy."[30]

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[26] V. J. Samar, *The Right to Privacy: Gays, Lesbians, and the Constitution* (Philadelphia: Temple University Press, 1991), p. 86.

[27] O. O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002), p. 29.

[28] Boling, p. 20.

[29] Samar, p. 86.

[30] Boling quoting J. Feinberg, p. 21, from his essay "Autonomy, Sovereignty, and Privacy: Moral Ideals in the Constitution?" (1983) 58 *The Notre Dame Law Review* 445.

Broader conceptions of privacy that extend beyond access to information and include restrictions to physical and/or spatial access affirm individual autonomy. Schoeman claims, "the most embracing characterizations of privacy include aspects of autonomy, particularly those associated with control over the intimacies of personal identity….privacy is the measure of the extent an individual is afforded the social and legal space to develop the emotional, cognitive, spiritual and moral powers of an autonomous agent."[31] Narrower conceptions of privacy limited to restrictions on access to personal information do not foster autonomous development in the same way[32], but can be said to support an autonomous life.[33] These different ways of thinking about privacy and its relationship to autonomy lead us to question whether privacy is an intrinsic or an instrumental good. I think privacy can be both, depending on context and the values and beliefs held by an individual. One commentator's analysis of the literature showed that privacy was largely viewed as an instrumental good by research advocates, while philosophers sought to make the case for privacy as an intrinsic good.[34]

On the standard liberal account[35], privacy is understood as enabling autonomy. An autonomous agent is one that is free to discover and pursue their own interests, compatible with a similar freedom for all others.[36] But as Joseph Raz notes, "autonomy is

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[31] Schoeman, p. 13.
[32] Ibid.
[33] Rössler, p. 72.
[34] D.E. Detmer, "Your privacy or your health –will medical privacy legislation stop quality health care?" (2000) 12:1 *International Journal for Quality in Health Care* 1.
[35] I am referring to the characterization of liberalism that has been presented so far and which is frequently encountered in the bioethics literature in discussions of autonomy and informed consent. I am not claiming that it *is* the 'standard' account of liberalism.
[36] Samar, p. 97.

possible only within a framework of constraints".[37] In pursuing one's interests our actions cannot encroach on the freedom of others to pursue their interests. Accordingly, privacy affords the space in which to follow these pursuits without those actions being incompatible with the freedom of others. Privacy in this sense posits a constraint necessary for autonomy; it is understood as setting limits to the actions that can be undertaken in public, and where such actions in private foster autonomous agency. For example, in pursuing a rock music career, I cannot simply take my electric guitar and play it loudly on the street, impeding traffic and preventing my neighbours from the peaceful enjoyment of their front yards. However, in the privacy of my own home, I can play the guitar at my leisure.

Some theorists question the value of privacy as defined in terms of autonomy. Boling asserts that conflating privacy with autonomy or liberty is not useful for showing what is distinctive about privacy.[38] In similar vein, Samar argues that it fails to explain why privacy can be important to persons and communities that do not value individual autonomy.[39] In this respect Nagel's view is instructive. He maintains that although privacy can play an important role in securing or preserving autonomy, it is not essential for it. It is, however, essential for selfhood. Privacy, according to Nagel, "serves to give each of us some control over the face we present to the world".[40] On Nagel's account, privacy is essential for cultivating an inner life. If our thoughts, feelings, and desires were continuously exposed to the outside world, there would be no distinction between

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[37] Raz, p. 155.
[38] Boling, p. 21.
[39] Samar, p.115.
[40] T. Nagel, *Concealment and Exposure* (New York: Oxford University Press, 2002), p. 4.

our intimate self and our public persona. The public persona is what we present to the world as a matter of social convention, and in Nagel's view, is essential for civilization. He notes that, "the public-private boundary faces in two directions –keeping disruptive material out of the public arena and protecting private life from the crippling effects of the external gaze."[41] Thus having the ability to shield ourselves from public scrutiny relieves us of the burden of having to 'put on the right face', and gives us the space for moral development.[42]

Schoeman sees privacy not as a condition for autonomy, but as a condition for intimacy to nurture relationships. According to Schoeman, the whole point of having privacy protection is to be able to relate to others in various ways. While autonomy suggests isolation, privacy "affords prospects of deeper relationships."[43] Schoeman's account of privacy appears to come closest to parting company with autonomy. However, he distinguishes between two sorts of privacy and advocates for the one he refers to as 'expressive-role privacy', where privacy entails restricted access from others with a point of allowing for self-expression.[44] The nurturing of relationships is thus part of the individual's self-expresssion. But we have to wonder to what extent this aspect of 'self-expression' differs substantially from autonomy if we understand that some component of self-expression includes deciding for oneself which relationships will be nurtured. In any case, Schoeman's account is not unlike Nagel's or other accounts of privacy that do not wish to essentialize the connection with autonomy. But whether

[41] Ibid, p. 15.
[42] Ibid, p. 7.
[43] Schoeman, p. 21.
[44] Ibid, p. 18.

privacy is necessary for selfhood, self-expression, moral development, dignity or integrity, the unit of focus is still the individual. None of these more nuanced accounts of privacy dispenses fully with liberal individualism.

2.3.1 Individualism: The Triumph of Autonomy

In giving some consideration to why the individualist conception of privacy has emerged as the leading framework in addressing privacy issues in healthcare, we can certainly point to the role of autonomy. Individual autonomy is a central concept within the liberal democratic tradition. Moreover, autonomy enjoys a starring role in bioethics, and this has had a profound impact on issues in healthcare and medical research. [45] Philosopher Onora O'Neill has written extensively on the central role of autonomy in bioethics. She has also been deeply critical of it. She writes,

> "[A]utonomy has been a leading idea in philosophical writing on bioethics; Trust has been marginal. This strikes me as surprising. Autonomy is usually identified with independence, and sometimes leads to ethically dubious or disastrous actions. Its ethical credentials are not self-evident."[46]

As noted earlier, autonomy has multiple definitions and comes in varieties. In the liberal tradition it is loosely understood as the capacity for self-determination, self-mastery, choosing freely, the freedom to choose, and independence.[47] In healthcare, these skills are essential for patients if they are to have some hand in controlling their fate. As the physician-patient relationship has increasingly moved from a paternalistic model where 'doctor knows best', towards an informed consumer model where the patient decides

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[45] O'Neill (2002), p.2.
[46] Ibid, p.ix.
[47] R.R. Faden and T.L Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986) p. 7.

from amongst a bevy of treatment options and chooses for herself, the principle of autonomy has gained some ground over the principles of beneficence and nonmaleficence that traditionally underscore paternalism. In the research context, the exercise of autonomy is protected and enshrined in several key declarations, and with good reason. Following the Nazi atrocities in the Second World War, the Nuremberg Code and later the Declaration of Helsinki made it explicit that no person may be compelled to participate in medical research against their will.

Individual autonomy is indispensable for a good life. Raz notes, "the autonomous agent is one who is not always struggling to maintain the minimum conditions of a worthwhile life."[48] He claims that the completely autonomous person is impossible,[49] but having some measure of autonomy is necessary to pursue the good as one sees fit, and everyone in a free and democratic society should be able to pursue their own good. No one would seriously contest that individual autonomy is a good thing, or the sort of thing that should be promoted; however, some theorists are critical of the increasing deference made to individual autonomy within healthcare, particularly at the expense of other important principles such as trust.[50] O'Neill argues that changes in medical practice that supposedly contribute to individual autonomy not only miss the mark, but may have undesirable effects. "They range from the huge reduction in compulsory detention of the mentally disturbed to the increased emphasis of formalized consent procedures not only for research participation but also for treatment; from proselytizing for greater patient

[48] Raz, p. 155.
[49] Ibid.
[50] O'Neill (2002), p. 36.

choice to demands that any advice or counseling be 'non-directive'.[51] Lysaught notes that autonomy has usurped the basic principle of 'respect for persons' and turned it into 'respect for autonomy'.[52] Other theorists argue that the increased focus on the interests of individuals neglects the interests of communities,[53] a sentiment commonly echoed by feminists and communitarians. Feminist bioethicists have been particularly vocal against some liberal conceptions of autonomy and the hyper-individualist stance they promote, calling for a reconfiguration of autonomy that is sensitive to relations of care, interdependence, and the particular contexts of women's lives.[54]

2.3.2 The Requirement of Informed Consent

In medical practice[55] individual autonomy is commonly reified in informed consent procedures. O'Neill asks, "what does the supposed triumph of autonomy in medical ethics amount to?"[56] In her view it amounts to the requirement of informed consent, a practice that can be somewhat problematic for the reasons that follow. First, it presupposes that informed consent somehow enables autonomy, where autonomy is construed in a narrow liberal fashion. According to O'Neill,

> "[T]hose who insist on the importance of informed consent in medical practice typically say nothing about individuality or character, about self-mastery, or reflective endorsement, or self-control, or rational reflection, or second-order desires, or about any of the other specific ways in which

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[51] Ibid, p. 36.

[52] M. T. Lysaught, "Respect: Or, How Respect for Persons Became Respect for Autonomy" (2004) 29:6 *Journal of Medicine and Philosophy* 665-680.

[53] T.M Wilkinson, "Individualism and the Ethics of Research on Humans" (2004) 16:1 *H E C Forum* 6-26.

[54] J. Christman, "Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves" (2004) 117 *Philosophical Studies* 143-164.

[55] I am referring here to healthcare and health research.

[56] O'Neill (2002), p. 37.

> autonomous choices supposedly are to be distinguished from other, mere choices. In short, the focus of bioethical discussions of autonomy is not on patient autonomy or individual autonomy of any distinctive sort. What is rather grandly called 'patient autonomy' often amounts simply to a right to choose or refuse treatments on offer…."[57]

On her account, informed consent does not necessarily promote autonomy, and she considers both concepts limited in significant ways. Having to choose from what she calls a 'smallish menu' of options, which is what informed consent passes for, hardly demonstrates an exercise in autonomy. It presupposes a rather minimalist interpretation of autonomy, which O'Neill claims suits the context of medicine just fine, since most patients, owing to their vulnerability, are unable to muster any robust version of autonomy.[58] This point seems to have been anticipated by Faden and Beauchamp in their influential theory of informed consent, as they take great pains to distinguish between *autonomous agents* and *autonomous actions*.[59] In their view, autonomous action is what is required for informed consent, and this can sometimes come from an agent that is less than autonomous.[60]

> "[A]utonomous persons can and do make non-autonomous choices owing to temporary constraints such as ignorance or coercion…It is no less important that some persons who are not autonomous can and do occasionally muster the resources to make an autonomous choice under circumstances calling for informed consents and refusals."[61]

But this distinction between autonomous agent and autonomous action will be unconvincing to theorists like O'Neill who are critical of what passes for autonomy in

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[57] Ibid.
[58] Ibid, p.38.
[59] Faden and Beauchamp (1986), p. 235-240.
[60] More precisely, Faden and Beauchamp argue that *substantially autonomous action* is what is required to give an informed consent since no one is fully autonomous.
[61] Ibid, p. 8.

medical practice, viewing the kind of choosing that goes on as inconsistent with truly autonomous choice. Furthermore, O'Neill claims that informed consent offers little justification for choosing, even if that choosing were autonomous in the ways presupposed. This is because informed consent is a *propositional attitude:* "it has as its object not a procedure or treatment, but rather one or another proposition containing a description of the intended procedure or treatment…In consequence consent, like other cognitive attitudes that take propositions as their object (such as knowing, believing, desiring or trusting), is *opaque*." [62] The opacity of consent lies in the description of what is consented to. A patient or research subject may understand what is being offered in a radically different way than it is intended to be understood. As such, she may not realize that in consenting to a proposition, she may also, from the perspective of the physician or researcher, be consenting to equivalent propositions or propositions entailed by the first. While it is evident that if *S* consents to *p* she does not consent to *q,* there is some question as to whether she consents to *q* if she consents to *p* and *p* entails *q*. The researcher may consider *q* implied by *p*, while the subject may not consider it at all, or understand it in a different manner. O'Neill illustrates this point with the example of a cancer patient. In consenting to chemotherapy a patient may truthfully claim she did not consent to the terrible side effects, even if these were carefully described to her. Perhaps the patient believed the side effects would be significantly less troubling, e.g. 'I understood I would be nauseous, but I never agreed to this!'

[62] O'Neill (2002), p. 43.

The implication of referential opacity is that the subject may not fully grasp what it is they are consenting to.[63] According to O'Neill, it shows that "informed consent can be quite superficial, fastening on the actual phrases and descriptions used, and need not take on board much that is closely connected to, even entailed by, those phrases and descriptions."[64] Thus the problem with informed consent is that patients and subjects may not fully understand *p* when they consent to *p*; whether that is because of propositional ambiguity, vulnerability, illness, or some other reason is of less importance than the fact that consent may turn out to be uninformed and hence invalid.

It is not only the theoretical problem of opacity that threatens the validity of informed consent, but its practical limitations, particularly in research. Often it is not possible to obtain consent; the subject may be deceased, untraceable, or does not wish to be contacted. There may be restrictions within the research itself, either in design or cost, such that obtaining consent would bias the study or place undue financial burden on the researcher. Lastly, the research may be excessively complex and difficult to understand, so that 'informed consent' is more of an ideal rather than a reality. O'Neill remarks, "…full disclosure of information is neither definable nor achievable; and even if it could be provided, there is little chance of its comprehensive assimilation."[65] As far as informed consent goes, O'Neill claims the best we can aim for is not to be coerced or deceived.[66]

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[63] Ibid.
[64] Ibid, p. 44.
[65] Ibid.
[66] Of course many people, myself included, would hope for a much higher standard in informed consent than simply not to be coerced or deceived. In Canada, *Reibl v Hughes* effectively established the standard of disclosure in informed consent as whatever information an objective reasonable person would want to know in the circumstance.

Taken together, the theoretical and practical limitations of consent present a challenge for 'informed' consent. One has to question its utility in particular research contexts. Clearly obtaining consent for participation in clinical research goes without saying; despite its shortcomings, we presently have no other way of ensuring that research participants are willing participants, at least willing to undertake the risks. But does informed consent serve– or should it – serve the same purpose in settings like observational health research where no contact with subjects takes place? If the role of consent is to afford protection to subjects by allowing them to decide what risks and harms they are willing to face in research, then some careful thought needs to be given to the non-interventional research context where the risks and harms are thought to be substantially less and can be removed or mitigated through other means.[67] In this context we may want to think about alternative forms of consent that allow individuals to choose the research they are willing to support, rather than turn to conventional project-by-project consent.[68]

If consent is meant to enable individual autonomy, we have already seen how this can be limited. A distinction might be made here between autonomy and *respect* for autonomy, where it can be argued that consent safeguards the latter. Faden and Beauchamp make this distinction, claiming that it is one thing to be autonomous and another to be respected as autonomous. "To respect an autonomous agent is to recognize

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[67] In observational health research there are strategies to minimize privacy threats, e.g. anonymisation of information and increased security for access and use of information.

[68] Willison et al (2007) report that the Canadian public is open to alternatives to project-by-project consent. Consider, for example, a general research consent form in the health record that specifies the types of research one is willing to participate in. The form can be updated at any time, and can be verified at doctor's visits or periodic intervals.

with due appreciation that person's capacities and perspective, including his or her right to hold certain views, to make certain choices, and to take certain actions based on personal values and beliefs."[69] However, this raises the question of whether seeking consent is the best way, or even the only way, to demonstrate respect for someone's autonomy.[70] In the observational research context, *respect for persons*, which is different from respect for autonomy[71], seems to me to be the crucial principle since we are dealing with information about persons and not persons themselves. In the use of someone's information we may strike at their dignity or integrity while leaving their autonomy intact. For example, in a particular study Jane may end up being classified in the group of morbidly obese people while she is simply slightly overweight. While this does not affect her autonomous agency one way or the other, it may come to offend her dignity. In aiming to preserve the dignity and integrity of persons, it is the principle of respect for persons that is better equipped to capture this. In the present context what we want is to demonstrate respect for persons while using their information in research; the challenge is whether we are able to do so without obtaining their consent. In chapter five I will sketch a broad conception of confidentiality which I believe can achieve this objective.

Having now outlined how individualism is endorsed in this particular liberal conception of privacy and in the principle of autonomy in bioethics, I will now consider how this framework predominantly informs the privacy discourse around health research.

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[69] Faden and Beauchamp (1986), p. 8.

[70] This question often came up in discussion amongst the team members of the CIHR-funded study *The Function of Academic Research Ethics Boards in Governing Privacy, Confidentiality, and Security Issues in Studies Using Personal Health Information.* Team members: D. Willison (PI), K. Brazil, M. Coughlin, C. Emerson, F. Fournier, E. Gibson, L. Schwartz, K. Szala-Meneok, and K. Weisbaum.

[71] I will consider this distinction in detail at a later stage.

Concerns about the threat to individual privacy are legitimate and warranted, as we noted in chapter one. These concerns are manifested in the literature, where the analyses usually transpire as a dichotomy between privacy interests and health research, mirroring the private/public distinction of the liberal tradition. Given this tendency, the conflict appears intractable. What we find are attempts to defend the individualist paradigm or the social cause with offerings of strained arguments that justify either the protection or subversion of privacy. There is little questioning of underlying assumptions, such as whether privacy is the key concept (rather than confidentiality), whether individuals are the unit of concern (instead of families, communities or groups), and whether the research is actually valuable (and how its value is determined).[72] Solutions tend to be framed around a 'balancing' approach, which inevitably are very difficult to craft, leave one side dissatisfied, and require continuous evaluation. There is substantially less exploration of alternative frameworks, such as universal compulsory participation in research,[73] or models banking on trust. We will be hard-pressed to find an adequate solution unless we re-think the problem.

2.4 The Individual Against Society: Framing the Privacy Issue

Many privacy theorists agree that the philosophy of individualism elevated the position of personal privacy in the 20th century.[74] The other major driving force, and the one that is especially relevant for the research context, is technological progress and

[72] It is beyond the scope of this thesis to consider all of these in turn. I raise these issues only to draw attention to the fact that more work is needed in this area.

[73] Not something I endorse, but for an interesting argument in its favour see C.D. Herrera "Universal Compulsory Service in Medical Research" (2003) 24 *Theoretical Medicine* 215.

[74] Samar, p. 60.

advances made in computing, what Michael Yeo and Andrew Brook refer to as the 'electronic panopticon'.[75] Consider:

> "[T]oday's war on privacy is intimately related to the dramatic advances in technology we've seen in recent years."[76]

> "[A]n early comprehensive look at the threat of computer-driven intrusion, identifies four recent developments that relate to the late twentieth-century concern for privacy: 1) massive record-keeping; 2) decision-making by dossier; 3) unrestricted transfer of information from one context to another; and 4) surveillance conduct at one level or another."[77]

Privacy in healthcare is an area of special concern given the ongoing proliferation of databases and the recent introduction of the electronic health record (EHR).[78] As well, people are more concerned with medical privacy than all other forms of privacy: "naturally we worry more about others finding out about diseases we have contracted or our genetic "flaws" than about our shopping habits or reading preferences."[79] Our 'genetic flaws' adds another layer of complexity to the privacy problem. The results of genetic testing and profiling can reveal potentially damaging information about individuals, e.g. a late onset disease.[80] Additionally, it can reveal information about relatives, and a hearty debate is unfolding about whether that information ought to be disclosed to family members, whom ought to disclose it, and what justification can be

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[75] M. Yeo and A. Brook, "The Moral Framework of Confidentiality and the Electronic Panopticon" in *Confidential Relationships: Psychoanalytic, Ethical and Legal Contexts.* Eds. C.M. Koggel, A. Furlong, and C. Levin (Amsterdam: Rodopi, 2003), p. 85.

[76] S. Garfinkel, *Database Nation: The Death of Privacy in the 21st Century* (California: O"Reilly & Associates, Inc, 2001), p. 5.

[77] Hixson, p.183.

[78] Etzioni, p. 142.

[79] Ibid, p. 139.

[80] Note that the information is damaging if it is used against the person, e.g. if one's insurance carrier denies us benefits, or it is the cause of psychological distress. Having knowledge of the information may be useful for confronting certain illnesses.

offered to disclose or not to disclose either way.[81] As well, the worry about social over-reaching has precipitated calls for the privacy of even 'public' information, i.e. information that is not sensitive, what some theorists refer to as the 'problem of privacy in public'.[82]

Owing to its history, the privacy issue in healthcare is largely analyzed in terms of a dichotomy: the interests of the individual against the interests of society. This tension between two competing but equally compelling goods forces a resolution in terms of a 'balance', where the scales can at any time tip in either direction. Consider Regan's analysis of how the process unfolded in the United States:

> "[T]he policy process began with an emphasis on the value of privacy, and much of the policy debate was framed in terms of an individual interest – privacy – in conflict with a societal interest – government efficiency, law enforcement, and an honest work force."[83]
>
> However,
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> "[I]n policy debates, the individual interest was on weaker footing than the societal interest. Privacy was on the defensive…."[84]

Similarly, Willison's analysis of the Canadian landscape through the examination of two key policy documents commissioned by the government in 2002[85] points to an effort to balance both sets of interests:

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[81] G. Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambride University Press, 2002).

[82] H. Nissenbaum, "Protecting Privacy in an Information Age: The Problem of Privacy in Public" (1998) 17 *Law and Philosophy* 559. See also A. Allen, *Uneasy Access* (New Jersey: Rowman & Littlefield, 1988.), Chapter 5.

[83] Regan, p. 22

[84] Ibid.

[85] *The Health of Canadians –The Federal Role Final Report Volume Six: Recommendations for Reform* (Ottawa: The Standing Committee on Social Affairs, Science and Technology, 2002). And, Romanow R.J. *Building on values: the future of health care in Canada* (Ottawa: Commission on the Future of Health Care in Canada, 2002).

> "[T]he Senate report framed the challenge for Canadians as: 'to set acceptable limits around the right to privacy on the one hand, and the need for access to information (by health care providers, managers, and researchers) on the other, to achieve an appropriate balance between them'. The Romanow report suggested that researcher access to person-oriented health information should occur only when there are sufficient safeguards in place and the system has demonstrated its ability to protect the privacy of individuals."[86]

And like Regan, Willison also came to the conclusion that privacy framed in this way is at a disadvantage. On the balancing approach, the scale usually tips in favour of the societal interest. Peekhaus has commented that this approach is a result of Canada's 'neoliberal policy agenda'[87] positioning biotechnology as a key driver of economic growth.[88] He argues that the privacy of personal information must often yield to biotech and economic imperatives, or be balanced against those interests, "an approach that is reflected in the majority of data protection policies and laws promulgated in the past 30 years."[89] Charles Raab concurs:

> "[P]rivacy costs are often underemphasized in light of the benefits that are held to accrue, whether to individual consumers or to citizens generally, from the more intensive exploitation of their own and others' personal information."[90]

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[86] Willison (2003), p. 344.

[87] Peekhaus does not define what he means by 'neoliberal policy agenda'. We can infer from his discussion that his view of neoliberalism is aligned with a philosophy of economic efficiency that favours social goods. He quotes from the *Leaders' Forum Steering Committee* (2004): "The advent of the new economic order is calling for a new and challenging public policy paradigm where social priorities such as health, education and skills development become the drivers of information-era growth and competitiveness, especially in terms of research and innovation."p. 48. This understanding of 'neoliberalism' is in remarkable contrast to the strand of liberalism we have presented so far that finds favour with individual interests. How do we reconcile this significant difference? Either we have incorrectly interpreted Peekhaus or neoliberalism corresponds to a perspective of liberalism that is radically different from the one surveyed in this thesis.

[88] W. Peekhaus, "Research in the Biotech Age: Can Informational Privacy Compete?" (2008) 28:1 *Bulletin of Science, Technology and Society* 48.

[89] Ibid, p. 51.

[90] C.D. Raab "From Balancing to Steering: New Directions for Data Protection" in *The Governance of Privacy: Policy Instruments in Global Perspective.* .C.J. Bennett and C.D. Raab, eds. (Burlington: Ashgate, 2003), p, 68.

Raab maintains that the concept of 'balance' implicit, and in many cases, explicit in policy and legal directives is an inadequate normative conception. He offers several interesting reasons for this deficiency, but it is the acute perception that the process of balancing involves various stakeholders, and each of these stakeholders brings a diverse set of values, interests, and power position to the table, that is noteworthy.[91] Far from achieving or nearing equilibrium, the scale will likely tip in favour of those with more power. If Peekhaus is correct in his assessment that the biotech agenda is the government's top priority, then we are likely to see privacy receive short-shrift.

For this reason, Raab advocates a shift from 'balancing' to 'steering', where the latter "builds on a system's self-policing mechanisms".[92] Steering derives from the authority of regulators (individuals or offices) who are endowed with powers to shift weight against built-in tendencies, which, from the tone of the discussion, tend toward the subversion of privacy.[93] Implicit in his proposal is the idea that it is possible to build on and refine current systems to ensure the protection of privacy.

Raab's steering approach posits that the individuals responsible for privacy protection are capable and willing of rigging, tipping, or altering the balance and moving it towards a new state of equilibrium. His approach depends on a precise interventionist strategy that involves, "monitoring, supervising, and inhibiting some data practices in ways that are not very different from traditional control methods."[94] The novelty in Raab's approach seems to come from a strict emphasis on governance and accountability,

[91] Ibid, p. 79.
[92] Ibid, p. 84.
[93] Ibid.
[94] Ibid, p. 85.

with publicity taking on a prominent role in highlighting cases of misdemeanor to send "signals to others to control themselves more effectively."[95]

There is something commendable in holding those we depend on to account, however, elements of the suggested steering approach may come across somewhat antagonistic. Governance and accountability are desirable traits to have in any health research model, and Raab's approach is laudable in its attempts to build on and improve current conditions. Moreover, it also endorses greater participation and input on the part of the public, advocating that data subjects become more educated about their data trail and 'better negotiators' in asserting their claims to privacy.[96] But this steering approach potentially leaves too much power in the hands of a few regulators, power which Raab envisions mitigating through extensive accountability measures[97]. This concentration of power looks similar to the power imbalance that was inherent at the stakeholder table in the balancing approach, and the criticism there was that those holding more power can get their way. Furthermore, trust is conspicuously absent from Raab's account. It is inconceivable that you could have a well functioning steering model that depends on 'steerers' the public does not trust. There is no evidence to suggest that reprimanding and subsequently publicising infringements on privacy deters violators, in this case, the steerers who fail to do their jobs satisfactorily. We have to be careful about promoting a

[95] Ibid, p. 86. See also O. O'Neill's discussion in chapter 6 of *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002).

[96] Raab, p. 85.

[97] He advocates for stringent codes of practice that are carefully regulated and maintained, and this may involve "overlaps and redundancy among checking mechanisms at different levels" but this should not be eschewed "for they may achieve objectives better than a single 'control room'" (p.86). He also endorses publicizing cases of privacy breaches and whistleblowing at all levels from ordinary employees to upper management. He concedes that this may be viewed as a distasteful path, but "the improved ethos that greater transparency and openness in bureaucracies could bring about would obviate the need for such informing"(p.87).

kind of overzealous accountability that can encourage a culture of distrust and suspicion,[98] so that if anything at all is deterred, it is researchers and managers from volunteering for 'self-policing'.

Graeme Laurie writes:

> "[P]rivacy is a problem. Or rather, privacy causes problems. It causes problems for sociologists, psychologists, anthropologists, philosophers, politicians, doctors, lawyers, governments, states, communities, groups and individuals. The problems that it causes relate to its definition, its function, its nature, its utility, its value and its protection."[99]

Laurie's astute observation resonates with what we have seen so far. In this chapter we have reviewed how a particular liberal conception of privacy premised on individualism drives the conflict between the individual interest in privacy against the societal interest in research. This leaves policy-makers scrambling in an effort to balance both sets of interests. Turning to theoreticians in the various disciplines is of little help; there is vast disagreement about the meaning and scope of privacy.

It is of interest that while privacy is triumphant in the academic world—with scores of tracts defending individual privacy and autonomy—in policy and practice societal interests seem to prevail. This illuminates an important point worth noting –that it is not always easy to put theory into practice. While convincing arguments can be deployed to show that privacy is a fundamental moral right, in practice that right can be overridden by other interests. Political principles involve evaluative trade-offs, and sometimes losses; what works best in the end may not be what the ideal theory

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[98] Onora O'Neill discusses this danger in chapter 6 of *Autonomy and Trust in Bioethics* (2002).
[99] Laurie, p. 1.

suggests.[100] This is what I think O'Neill has in mind when she criticizes concepts such as autonomy and informed consent. In theory, individual autonomy can be robust and consent is truly informed, valid, protective of autonomy, and so forth; however, in practice the reality is less than that. And in practice, privacy appears to be at a disadvantage, at least in the balancing approach where social interests tend to tip the scale. Raab suggests moving towards a steering approach, but this too is not without challenges. I think we need to steer in the direction of confidentiality. But first, we need to consider the value of privacy.

[100] There is a difference between arguing that privacy ought to be protected and arguing how best to protect privacy. The first is a moral question while the second is a policy issue. In many discussions of applied ethics this subtle distinction is not always observed. I am grateful to Wil Waluchow for bringing this to my attention.

-- Chapter 3 --

The Value of Privacy

In the last chapter I sketched a general conception of privacy as understood from a particular perspective of liberalism, and briefly examined the connection with autonomy. This was instructive for understanding how the privacy issue in research is framed and analyzed. We have yet to consider the value of privacy within the context of our analysis. Expressing concerns about threats to individual privacy in health research presupposes that privacy is something of value and worth protecting. We have already noted that privacy can be valuable for the preservation of autonomy and promotion of human flourishing. In this next section, I shall consider the meaning and value of *informational privacy*[1], which is the strand of privacy that is germane to our analysis. Following Beate Rössler's theory of privacy, I suggest that the meaning of privacy commonly encountered in discussions of privacy in health research is: 'that something counts as private if one can oneself control access to this 'something'', where the something represents information about ourselves.

It is thought that the loss of control with respect to one's personal information adversely affects autonomy, but it is not only autonomy that is at stake. Violations of informational privacy represent failed expectations in the knowledge we believe others have about us, and thus can threaten dignity and be experienced as an abuse of trust.

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[1] I note informational privacy to distinguish it from other forms of privacy, e.g. decisional, physical, etc…and to keep with current trends of referring to the privacy of one's information as *informational privacy.*

3.1 Meanings of Privacy

In her engaging book, *The Value of Privacy,* philosopher Beate Rössler presents a liberal account of privacy that attempts to delineate the meaning of privacy that can 'capture its full range'[2] thus it is informative for the present context. Rössler considers the various approaches to defining privacy and draws what she sees as the key elements from each one to propose a definition of privacy that is suitable for many contexts in western-liberal democracies. This is an important step, since many theorists agree that there is little chance of adequately analyzing the privacy problem in research until there is some consensus about its definition and meaning. Other theorists believe that attempting to give a precise definition of privacy is untenable and undesirable. In any case, it is useful to have a clear understanding of a specific theory of privacy to better situate its value in the present context.

According to Rössler, there are two distinct semantic models that inform the predicate 'private' in everyday language. The first she characterizes as an 'onion' model because one is able to discern between different layers of privacy. At the core of the onion model is the realm of personal or bodily intimacy, a second layer that is the family or intimate relationships, and the outer layer is comprised of civil society, which counts as 'private' with respect to intervention from the state. In the second model, "the term 'private' is predicated of actions or decisions that we may take or carry out no matter where we happen to be."[3] The first model describes privacy in spatial terms, and the

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[2] B. Rössler, *The Value of Privacy.* Trans. by R. Glasgow (Oxford: Polity, 2004), p.5.
[3] Ibid, p. 6.

second in terms of dimensions of action and responsibility.[4] Rössler argues that the full range of meaning relating to 'privacy' can be systematized under the two semantic models according to three different aspects of reference: i) modes of action or conduct; ii) knowledge; and iii) spaces.

A systematization of the term, however, does not bring us any closer to a definition. In the philosophical literature definitions of privacy usually correspond to narrow aspects of its meaning, which we noted in the previous chapter, e.g. restricting the access of others or nurturing intimate relationships. Rössler is critical of such popular theories, claiming that some crucial dimensions of the concept are left out. She favours what she describes as those theories "that aim both at a general meaning of the term and at a specific definition."[5] She proposes the following definition of privacy: "Something counts as private if one can oneself control the access to this 'something'".[6] Rössler claims that the strength of this definition lies with the ability to control unwanted access, rather than the idea of separating the individual from some descriptively public realm. This has relevance to our analysis, since we begin with the premise that health information is a private interest in a public domain. In Rössler's definition, the concept of 'control' illuminates the normative content of privacy. Accordingly, "the word 'can' must also be understood in the sense of 'can and/or should and/or may."[7] Thus information about me is private if I can and/or should control access to it, even if in fact I can't. The crucial feature of this definition is the normative weight of the 'should'. For

[4] Ibid.
[5] Ibid.
[6] Ibid.
[7] Ibid.

information about me to be legitimately circulated, it must have my consent.[8] As such, this normative dimension of privacy enables us to define it in terms of *decisional* privacy, *informational* privacy, and *local* privacy.[9] [original emphasis]. Decisional privacy involves restricting interference with our decisions and actions. Informational privacy is in Rössler's words, "…the right to protection against unwanted access in the sense of interference in personal data about themselves, in other words access to information about them they have no desire to see in the wrong hands."[10] And lastly, local privacy refers to protection against unwanted access into our spaces, where spaces are understood completely non-metaphorically. Evidently all three meanings of privacy have relevance and application in research. Having decisional privacy is fundamental in deciding whether to participate in research, for example. An encroachment on local privacy can be said to occur when a clinician-scientist enters a patient's hospital room to recruit the patient for a research study. We are eminently concerned, however, with informational privacy since we are dealing with the use of personal data in research.

Rössler's restricted access account coupled with the element of control adequately captures the meaning of privacy that is operational in the privacy-versus-research conflict; we can see this clearly from the privacy side of it that calls for informed consent to use the data. The characterization of privacy as the desire not to have information fall into 'the wrong hands', however, is perhaps too hostile for the research context. It can be suggestive that access to information that is not within our control is decidedly malicious.

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[8] Ibid.
[9] Ibid, p. 9.
[10] Ibid.

This claim is contestable; arguably the majority of researchers have no mal-intent towards subjects.

3.1.1 Private and Public Conventions

Rössler cautions that her definition of privacy must be understood as conventional, meaning that what is 'private' and what is 'public' varies from one society to another, or from time to time. Liberal societies may have culturally ingrained privacy norms, but there is ambiguity about what counts as 'private' and what counts as 'public'. Thus there is tremendous uncertainty about what information about myself I can legitimately claim to want to control against unwanted access. I may not want the postman to know my birthday, and have a rightful claim to control access to that information by denying it when he asks. However, do I have an equally rightful claim to control access to knowledge of my address when the postman is well aware of the number on my house when he deposits the mail in my mailbox? Rössler's account states that something counts as private when one can oneself control access to it. Clearly, we can control access in the first instance, but not in the second, thus one's home address is not something that ought to be considered private. Or is it? Rossler argues that the 'can' has normative import and can be understood as a 'should' and/or 'may'. Suppose we ask: 'should' my home address be something that I can control access to because it is private? We are likely to receive different answers, but most people will agree that the number on my house, something which is in plain view of the public, is not private *qua* private. We can explain this through conventions: liberal societies have conventions and it is an

established norm to consider the numbers displayed on houses public items, even while conceding that homes are private dwellings. The point to be gleaned from all of this is that what counts as private varies with social context. In some contexts information cannot be protected as private, even if we wish it could be.

Questions about what is private in the health care setting are far more complex. To say something counts as private if I can myself control access to it, leaves very little, in fact, that is private. For the most part, patients cannot control access to information about themselves. To receive care, patients are required to divulge intimate and personal details about themselves, sometimes far beyond what they feel comfortable disclosing, even within the therapeutic relationship which is bound by the principle of confidentiality. Patients do not have ownership of their health record, or even the information contained therein.[11] There is extensive communication within the circle of care for teaching and research purposes which the patient does not specifically authorize. And finally, health records are held and maintained by physicians and other health care workers at various institutions; from a purely physical or spatial point of view, these places are not 'private'.

On a strict normative interpretation of Rössler's definition something is private if I 'should' myself control access to it. On this understanding health information may be considered private because many would agree that one should control what happens to their personal data. However, the matter is much more complicated. How do we decide what exactly is private? Is it the entire record? If not the entire record, then what aspects

[11] W.W. Lowrance , *Learning from Experience* (2002), p. 3. Patients do have a right to inspect data about themselves and correct misinformation.

or information 'should' the patient control? This is the crux of the privacy problem. There is no consensus on what information should be controlled by the patient, i.e. what information uses should consent be sought for. Rössler's account will not give us the answer, for as she notes, her definition must be understood conventionally. While this is useful for deciding on many issues of privacy, the research context is unique in that there is, in many respects, no convention. Patients, research subjects, clinicians, and researchers all have different ideas about what counts as private. Even Research Ethics Boards who are supposedly uniformly guided by the same set of rules show widespread disagreement on what is private.[12] Information which is private in one research study, may be considered less so in another; it well depends on the research question. For example, I may object to use of my vital statistics information in a study on mental health for fear of stigma, but may not care whether it is used in a study on osteoarthritis.

As well, recent changes in the legal landscape have altered what may have been considered conventional. For example, 'fishing expeditions' through medical records may not only have been permitted, but perhaps encouraged in research intensive environments. That is no longer the case in some jurisdictions.[13] The current and widespread objection from researchers that their research efforts are hampered on account

[12] Willison et al, "Access to Medical Records for Research Purposes: Varying Perceptions Across Research Ethics Boards" (2008) 34:4 *Journal of Medical Ethics* 308.

[13] In Ontario, the health privacy legislation that came into effect on November 1, 2004, *Personal Health Information Protection Act (PHIPA)* disallows trolling through health records in search of research questions.

of strict privacy rules pertaining to access and use of information shows that previous convention has changed.[14]

Since privacy is conventional, and in many respects, a contestable concept, it is unlikely that its precise meaning can ever be specified. It is advisable thus to acknowledge these facts upfront when deciding on questions of privacy and confidentiality, particularly where they figure in public policy.

3.2 The Value of Privacy

Why do we value privacy? According to Rössler, "we regard privacy as valuable because we regard autonomy as valuable, and because autonomy can only be lived out in all its aspects and articulated in all its senses with the help of the conditions of privacy and by means of rights and claims to privacy."[15] Applying this to the present context, privacy protects autonomy in those respects in which the exercise of autonomy is dependent upon my control of the access of others to me, or more precisely, to information about me.

One implication of Rössler's claim is the idea that if one gives up aspects of one's privacy or if privacy is breached in some way, then at the same time we forfeit aspects of our autonomy.[16] This presents a formidable challenge for research that can potentially

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[14] See A.S. Gershon and J.V. Tu, "The effect of privacy legislation on observational research" (2008) 178:7 *Canadian Medical Association Journal* 871-873; C. Verity and A. Nicoll, "Consent, confidentiality, and the threat to public health surveillance" (2002) 324 *British Medical Journal* 1210-1213; J. Kaiser, "Privacy Policies Take a Toll on Research, Survey Finds" (2007) 318 *Science* 1049; and C. Davies and R. Collins, "Balancing potential risks and benefits of using confidential data" (2006) 333 *British Medical Journal* 349-351.

[15] Rössler, p. 10.

[16] Ibid, p. 74.

encroach on privacy, since depriving someone of autonomy is incompatible with fundamental tenets of ethical research involving human subjects. Rössler queries: "Why do we find it injurious when medical data concerning us is passed on to third parties, and why is it unpleasant to be the object of gossip? … Why do we feel upset, shamed, injured, scarred, insecure or manipulated once we realize what has happened?"[17] A central feature of an autonomy based account of privacy is control, and with respect to loss of informational privacy, a loss of control over what other people come to know about us translates into a loss of autonomy. Unlike a clinical referral, where your information is passed on to aid in your care, it is not essential for researchers to have knowledge of your personal information. In the end it may be that the information is used responsibly, and for research that you whole-heartedly support, but you may still experience a loss of privacy as a of loss of control. Consenting for the use of one's information is one way individuals can retain control over their data, and hence protect their autonomy.

Rössler's theory, like many liberal theories of privacy, designates privacy as a requirement to secure autonomy. Privacy may not be sufficient for autonomy, but it may very well be necessary. In the previous chapter, I highlighted a common feminist critique of privacy: that it has in the past been a tool to oppress and subjugate women, thus demonstrating that the availability of privacy is insufficient to support autonomy. However, some degree of privacy is surely necessary to cultivate autonomous agency. Consider whether one could be sexually autonomous in the complete absence of privacy? Privacy is valuable, at the very least, because it contributes to autonomy.

[17] Ibid, p.111.

3.2.1 Loss of Control and Failed Expectations

The ability to control the access of others to our information is a key feature of Rössler's theory, and we need to examine what is presupposed in the idea of control. If informational privacy is indeed about control, it suggests that people have the control necessary with respect to information about themselves. Having control implies, at the very least, the ability to exercise it. I would add that it points to having actively thought about what it is you want to control. Yet a model of informational privacy premised on control does not completely resonate with what is actually the case in observational health research – where patients are unwittingly conscripted as research subjects. The majority of patients are unaware of the control they have over their personal information, and among those that are, it is unclear how many actually choose to exercise it. It is only when a privacy breach comes to light that individuals become aware of the control that they have (or lack) with respect to their information. Most are entirely oblivious to the research. When a serious breach occurs, people are shocked and dismayed to learn that sensitive information about them has circulated so easily and so extensively beyond what they believed to be the secure filing cabinet of their family physician. The disappointment and anger that accompanies the discovery of such a breach can be explained not only in terms of a loss of control, but also in reference to the abuse of trust that has taken place. The patient usually laments that her family doctor 'has let her down' in allowing the transgression. Rössler is correct in asserting that "what is decisive, is that this means that her *expectations*, where these expectations concerning the knowledge

others have about her prove to be false, are disappointed or come to nothing"[18][original emphasis]. This notion of a failed expectation can explain those instances where a loss of control does not accurately describe the experience of patients who sustain a loss of privacy, i.e. patients who were not thinking about control with respect to their information, but had trusted in someone to protect it.

Thus, in addition to loss of control, violations of informational privacy are also understood as false or disappointed expectations with respect to the knowledge that others have about us. Rössler claims that, "a specific feature of violations of informational privacy, in other words, is that they have to do with expectations and assumptions regarding what other people or institutions know about the person, how they acquired their knowledge, and thus *what relation* they bear to that person *on the basis of this knowledge*"[19] [original emphasis]. The reference to relations and expectations is instructive. Patients reasonably expect that knowledge about them is shared between other health practitioners as necessary for clinical care. We cannot say with any certainty that they expect knowledge to be shared with researchers or other third parties within the health system, but outside of the treatment circle. We can state with some confidence that no one expects information to be shared willy nilly outside of the institution, e.g. with pharmaceutical company employees. Suppose the latter scenario transpires; we can say that the physician, researcher, or institution failed to live up to the expectation of privacy and confidentiality of the individual by sharing his information with outsiders. The individual may have had expectations of controlling what is done with his information, so

[18] Ibid.
[19] Ibid.

that the loss of control in this case is also a failed expectation. What is certain is that a loss of informational privacy is a failed expectation, whether or not it is also perceived as a loss of control. Failed expectations can result from an abuse of trust, from the individual having unrealistic or exaggerated expectations, or from some other circumstance that results in a violation but is not attributable to an abuse of trust. We are interested in examining the first reason.

Violations of informational privacy that result from an abuse of trust demonstrate failure to show respect for the individual.[20] Respect for persons recognizes their value and dignity as persons, so that a demonstrable lack of respect is an affront to the dignity of the person. This offense to one's dignity is captured in the sense of embarrassment or shame the person feels once the transgression is discovered. Nagel is correct in his assessment that the selfhood of the person is compromised when the public persona is shattered and others have access to our inner vulnerabilities. Transgressions that occur without the knowledge of the individual, which can happen in observational health research, occur in some cases because of an abuse of trust. These instances reflect an attack on dignity and need to be explicitly recognized as such. In many discussions of privacy violations in research, the transgression is thought to undermine individual autonomy. The fact that such violations also represent an affront to dignity needs to be acknowledged. Maintaining the dignity of subjects intact in this context depends on respecting subjects as persons and not abusing their trust. The realization of this important fact will impact how information is handled and used in research.

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[20] Such violations may, at the same time, indicate a felt loss of control.

In many observational health studies the individual is unaware that information about her is accessed, used and disclosed. If some uses cast a negative light on the individual or the community to which she belongs, the violation goes beyond any tangible consequences that may follow. Despite not being aware of it, the individual is harmed. For there is something inherently wrong in not knowing how others perceive you, particularly if they perceive you in a manner in which you do not wish to be seen. Rössler claims, "…it is not simply that the 'data record' of the person is damaged, but the person herself is violated in her knowledge, for there is something that *she does not know* that *other people do.*"[21] [original emphasis]. As a result, the individual holds false expectations about how other people view her. In cases where the individuals are known to each other, Rössler argues that the person holds false expectations about the way other people behave towards her and about whom she is dealing with. As an illustration, consider Hannah, who has a neighbour Joyce, that was recently hired as a nurse at the local hospital. Recently Joyce worked on a research study where she visited many local family practitioners offices and extracted personal information for a study involving physicians that have hospital privileges. Although the study itself did not collect particularly sensitive health information, the research staff had access to the entire health record to extract the relevant information. Unbeknownst to Hannah, Joyce pulled Hannah's chart for the study and saw that Hannah has a history of mental illness including two hospitalizations for severe depression and one suicide attempt. Hannah has no idea that Joyce is apprised of this very sensitive information, and so her expectation

[21] Ibid.

that Joyce knows nothing of her troubled past is false. In a significant way, her interactions with Joyce are disingenuous. Hannah is unaware that Joyce no longer allows her daughter to attend at Hannah's house for play dates with Hannah's daughter because she questions Hannah's mental stability. On Hannah's part, it is unjust that she is unable to respond to Joyce's prejudice and continues to interact with her under false expectations. The expectation that we have about what knowledge others have about us concerns our interests in not being misled in our beliefs about what others know, not being harmed as a result of them holding that knowledge (e.g. blackmail), and in maintaining our dignity intact. The loss of control over what knowledge others acquire about us is a significant part of the violation, but not its only morally relevant aspect. Importantly, the violation also involves a loss of dignity in our failed expectation of what we believe others know or not know about us.

To see how it is dignity, and not only autonomy that is at stake, consider the example that Rössler believes shows the connection between violating privacy and infringing on autonomy. She recounts the story of Tommy, who believes himself to be alone and unwatched in his room, but really he is being spied on by two neighbourhood kids through the keyhole. Tommy is prancing around the room, watching himself in the mirror give and execute military commands. Tommy engages in this behaviour because he does not believe he is being watched; if he thought for one moment that he was under surveillance he would behave otherwise. According to Rössler, his interaction with his friends is disrupted from this moment on, since his expectations regarding what they know about him are false. Further, this implies that one aspect of his capacity for self-

determination is violated. Tommy behaves the way he does because he believes to be acting privately. Thereafter, he behaves the way he does because he believes he acted privately; and his actions with respect to his friends are premised on the belief that they do not know about his private behaviour. If Tommy had any inclination that his friends knew about his private actions, he would behave in a different manner towards them.

Rössler's assessment is correct, but her interpretation misses an important element –dignity. Her interpretation does not give explicit attention to the way in which Tommy might feel embarrassed and his dignity injured, and how his friends' failure to respect his privacy demonstrate a lack of respect towards Tommy and their relationship. By peeping on him, his friends did not afford him the respect he was entitled to as their friend. This is an affront to Tommy's dignity, and it does damage to the trust in their relationship. This is so whether or not Tommy is aware of the transgression.

Rössler's interpretation is focussed on how Tommy's failed expectations about what his friends know about him impact his autonomy. Because he is unaware of what they know, Tommy continues to act in the relationship as he always does; his ignorance of the violation prevents him from choosing to relate to his friends in a different way. In this sense, Rössler is correct in asserting that he is less autonomous. However, failed expectations of this sort may be indistinct from other inaccurate or incomplete beliefs we hold, and that may or may not affect our actions. We make choices and act based on the available information; if it turns out we have been deceived, our choices and actions may not be the ones we would have pursued. But all this says is that we would have made other choices, not that we were prevented from choosing in the first place. In discovering

the violation, Tommy may choose to relate to his friends differently than he has in the past; but then again, he may not. Even with the knowledge of the transgression, Tommy may continue to relate to his friends in the same way. To be clear, Tommy's autonomy is in some measure adversely affected by the violation. However, I think the more significant implication of Tommy's violation is that his relationship with his friends is disingenuous; they abuse his trust and fail to respect him as a friend. In this they offend his dignity.

The two examples illustrate how the dignity of the person can be damaged in violations of privacy. Individual autonomy is also subverted, in the loss of control over one's information and in failed expectations about the knowledge others have about us. But while an infringement on autonomy is damaging to individuals, as the two examples in this chapter illustrate, the failure to show respect for persons and corresponding affronts to dignity can impact individuals and entire groups of people.[22] Moreover, it is commonly said that privacy violations adversely affect individual autonomy, but affronts to human dignity are acknowledged less frequently. We need to explicitly recognize that dignity is at stake in violations of informational privacy. Privacy is thus valuable not only for autonomy, but also for one's dignity.

In this brief chapter we have considered the meaning and value of privacy, and observed how privacy is valuable for maintaining autonomy and dignity. In the next chapter I turn my attention to confidentiality and consider its conceptual and normative framework.

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[22] This is an important point that we shall consider later.

--Chapter 4 –

Confidentiality: 'The Second Concept'

In her historic work *The Second Sex* Simone de Beauvoir tells us that woman is defined relative to man, differentiated only in reference to him, emerging as the incidental 'other'.[1] In similar fashion the principle of confidentiality appears as 'the second concept', sitting in the shadow of privacy, the undisputed master concept in this debate. In the context of research, confidentiality is rarely discussed as a stand-alone concept, but usually as an adjunct to privacy. Consider Section 3 of the Tri-Council Policy Statement – "Privacy and Confidentiality": respect for privacy is emphasized to a noticeably greater extent than the duty of confidentiality. Article 3.6 on data linkage does not mention confidentiality at all; the concern is with 'new threats to privacy' and the 'ethical obligation to respect privacy'.[2]

It is hardly surprising that confidentiality appears as the residual concept. In contrast to many central concepts in bioethics such as autonomy and beneficence, it has received considerably less attention. In the philosophical literature, confidentiality has not been conceptually explored in any depth[3]; the bulk of the work is focused on its application in various medico-legal contexts where analyses have tended to focus on

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[1] S. de Beauvoir, *The Second Sex,* in *Gender: Key Concepts in Critical Theory* ed. By Carol. C. Gould (New Jersey: Humanities Press, 1997) p. 3-15.

[2] TCPS, Article [3.6].

[3] Consider that a search in the *Philosopher's Index* turns up three times as many hits for privacy as compared to confidentiality; 969 hits for privacy and 309 hits for confidentiality. April 28, 2008.

considerations of its force and justified omission in these domains.[4] In the previous two chapters we saw how privacy has come to be the 'master' concept, dominating the discourse in this debate. But as Yeo and Brook observe, confidentiality "deserves a *lot* more attention than it is receiving"[5][original emphasis].

Confidentiality is often conflated with privacy or taken to be a mere instantiation of it.[6] However, this narrow conception is mistaken. In health care, the moral and practical significance of confidentiality extends beyond the mere protection of individual privacy and is relevant outside of the therapeutic context. The implications of taking the principle of confidentiality seriously in observational health research have not been considered.

In this chapter, I examine how confidentiality is distinct from privacy, and why it is significant for this debate. I begin by considering the definition and conceptual elements of confidentiality. Our analysis shows that vulnerability, trust and fidelity are central elements to the concept of confidentiality. In contrast, autonomy which is the key element that attaches to privacy is far less prominent in confidentiality.

It is noteworthy that the vast majority of philosophical work on confidentiality is centered on the therapeutic relationship in the clinical context. This is a theoretically significant point not to be missed. There is a crucial difference between the norms that apply in the clinical and research contexts respectively, in particular with reference to the

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[4] K. Kipnis, "A Defense of Unqualified Medical Confidentiality" (2006) 6:2 *American Journal of Bioethics* 7.

[5] M. Yeo and A.Brook, "The Moral Framework of Confidentiality and the Electronic Panopticon" in *Confidential Relationships: Psychoanalytic, Ethical and Legal Contexts.* p. 85.

[6] C.M. Koggel et al (eds) *Confidential Relationships : Psychoanalytic, Ethical and Legal Contexts* (Amsterdam: Editions Rodopi B.V., 2003), p.8.

nature and status of the relationships involved and the attendant expectations. I am thus obliged to consider how insights from the therapeutic context might extend to our analysis in observational health research. I will draw mainly from the body of work that has concentrated on confidentiality within psychotherapy and mental health. This proves instructive in many ways; mental health remains a sensitive issue, both within medical practice and research, and can speak to a variety of issues with which our analysis is concerned, such as stigma and the potential for group harm.

Once I have outlined the conceptual content of confidentiality, I move on to consider the foundation for its moral framework. Following Yeo and Brook's analysis of confidentiality in the information age, I examine two distinct conceptualizations that roughly align with consequentialism and deontology. My analysis shows that consequentialism offers the most promising framework for our research context, but it is lacking in important deontic principles (e.g. respect for persons). In the chapter that follows I attempt to remedy this deficiency through a deontological revision of the framework.

4.1 The Nature of Confidentiality

> *All that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal.*[7]
>
> *Hippocrates, 4th century B.C.*

[7] Original Hippocratic Oath, translated from the Greek. Available: http://en.wikipedia.org/wiki/Hippocratic_Oath

4.1.1 Origin

Confidentiality is a prominent duty in many professional codes of practice, particularly those of the medical and legal professions. It can be traced back to Ancient Greece to Hippocrates, who is credited with writing the oath that spells out what a good physician is and does, and several of the key principles guiding the practice of medicine today, e.g. truth-telling and non-maleficence, can be found in the oath.[8] The Hippocratic Oath has evolved into several modern versions that more accurately reflect the complexity of today's healthcare, one that Hippocrates could not have imagined, yet the fundamental tenets and spirit of the original oath remain.[9] Its survival into the 21st century is a testament to the enduring significance of the principles in medical practice.

The origin of confidentiality in the patient-doctor relationship has been decisive in maintaining its prominence in client-professional relationships, e.g. attorney-client and therapist-client, where privileged communication is essential for the proper functioning of the relationship and the attainment of desired goals. Lasky and Riva assert, "the concept of confidentiality is fundamental to all forms of psychotherapy",[10]and Yeo and Brook agree that, "unless a patient has complete confidence in the confidentiality of the process, he or she will not be candid about matters that are embarrassing or shameful and certainly not about matters that may involve moral turpitude or illegality."[11]

In human subject research, confidentiality is also deemed important. It is considered an ethical obligation, and is sometimes not viewed with the same urgency as

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[8] Ibid.
[9] Ibid.
[10] G.B. Lasky and M.T. Riva, "Confidentiality and Privileged Communication in Group Psychotherapy" (2006) 56:4 *Internaional Journal of Group Pscychotherapy* 455.
[11] Yeo and Brook, p. 85.

in clinical care where it is viewed as a fiduciary duty –though the relationships between subject and researcher, and subject and health institution are fiduciary in nature.[12] This is because the goals of treatment are different from the goals of research. While the maintenance of confidentiality is essential for the provision of good care, confidentiality is thought essential in research for satisfying ethical requirements and not necessarily for securing benefits for the research subject. In many cases the subject does not directly benefit from the research – as in observational health research. Consequently, researchers are more concerned about obtaining informed consent, preserving autonomy and preventing harm.[13] In contexts such as observational health research, where the researcher and subject have no contact with each other, the researcher may not even perceive that she owes a duty of confidentiality to the unseen subject.[14]

The maintenance of confidentiality by health practitioners can be justified not only in terms of the patient's privacy interest, but also in the interest of the public good in preserving the integrity of the relationship. "[I]t is in the interests of all patients, present and future, to expect the medical profession to respect their confidences for the sake of the preservation of the general concept of the confidential doctor-patient relationship."[15] This supports the idea that confidentiality is not merely about protecting individual interests. In seeking to protect relationships, confidentiality nurtures the wider social

[12] Researchers and health institutions have special relationships with subjects in which they are required to look out for the best interests of the subjects. The duty may be prescribed by law. See "Law of Fiduciary Obligation" in *The Canadian Encyclopedia*. Available: http://www.thecanadianencyclopedia.com/index.cfm

[13] Researchers are well aware that subjects can be harmed by a breach of confidence, but here I am referring to harm in the narrow sense one might think about in a clinical trial, which is physical or psychological harm, e.g. side effects from interventions.

[14] This is an important point to which I will return later.

[15] C. Cordess, "Confidentiality in Contemporary Practice" in *Confidentiality and Mental Health*, ed. C. Cordess (London: Jessica Kingsley Publishers, 2001), p. 28.

interest that individuals have in trustworthy social institutions. Levin et al take a more practical view of confidentiality and assert that its justification is far less noble than usually assumed. They claim:

> "[T]hat the notion of confidentiality in the helping profession has its roots in pragmatic considerations about the requirements of professional practice and treatment is inescapable. The fundamental issue appears to be not patients' privacy or a sacred oath of secrecy; rather, it is the built in need for the individual patient's *cooperation* in order for the treatment to work. The work of the healer simply cannot be accomplished without free access to information that individuals, even in primitive collectivist societies, do not spontaneously divulge."[16]

3.1.2 The Elements of Confidentiality

Confidentiality is defined in the *Oxford English Dictionary* as 'having the quality or state of being confidential', where confidential is characterized by being "entrusted with secrets" or "enjoying the confidence of another person."[17] CIHR defines confidentiality as "the obligation of an organization or custodian to protect the information entrusted to it and not misuse or wrongfully disclose it".[18] Two fundamental elements of confidentiality are detectable in the terms 'obligation' and 'entrusted'. An obligation is a moral duty, a binding demand placed on an agent. Obligations can be differentiated in terms of their moral weight or stringency. Some obligations are absolute, 'categorical' requirements as Kant maintained, that *must* be satisfied without

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[16] C. Levin et al, "Questions and Themes" in *Confidential Relationships* (Amsterdam: Rodopi, 2003), p. 2.

[17] Oxford English Dictionary. Available: http://dictionary.oed.com.libaccess.lib.mcmaster.ca/cgi/entry/50046955?query_type=word&queryword=confidentiality&first=1&max_to_show=10&single=1&sort_type=alpha

[18] CIHR Best Practices for Protecting Privacy in Health Research" (2005), p. 110.

exception.[19] Other obligations are discretionary, such as being kind or generous, and afford some latitude in compliance, the so-called hypothetical imperatives.[20] We can further distinguish the nature of obligations in terms of their origin. Some obligations are legal, e.g. filing a yearly tax return, some are political, such as voting, and some may arise from specific roles or relationships, such as parental obligations. Confidentiality crosses many of these domains. It is a legal obligation, but it is not absolute.[21] Yet it would be incorrect to consider confidentiality a hypothetical imperative; it clearly has more than discretionary force as a moral obligation. Furthermore, it arises within a fiduciary relationship, though it need not be well-defined or specified, as in the hospital-subject or observational researcher-subject relationship.

Trust is fundamental in a confidential relationship, perhaps its most important element. Without trust in the relationship, trust in the person within whom you confide, there is no impetus for self-disclosure. The provision of healthcare would be seriously impaired if patients felt they could not be forthright and failed to disclose important details about themselves to their care-providers. The paradigmatic relationship of trust is the doctor-patient relationship. Consider O'Neill's depiction of the prototype relationship:

> "The patient approaches the doctor knowing that the doctor is bound as a matter of professional oath and integrity to act in the patient's best interests, even that the doctor stands at risk of disgrace or disqualification for serious failure in this regard. Although there are always contractual and financial arrangements linking doctor and patient, or doctors and the

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[19] I. Kant, *Grounding for the Metaphysics of Morals,* translated by James W. Ellington (Indianapolis: Hackett Publishing Company, Inc., 1993), p. 25. The Kantian interpretation of duty is not accepted by all. Many regard all moral obligations as categorical, but potentially in competition and capable of being outweighed by the more pressing moral competitor.

[20] Ibid.

[21] Kipnis, p.7; and M. Habiba and M. Evans, "The Inter-role Confidentiality Conflict in Recruitment for Clinical Research" (2002) 27:5 *Journal of Medicine and Philosophy* , p. 567.

> institutions that organize medical care and employ them, the doctor-patients relationship is supposed to trump any considerations of self-interest and gain. It is a professional relationship that is supposed to be disinterested, long-lasting, intimate and trusting."[22]

O'Neill's description partially illuminates the substance of trust in the professional relationship. It is trust premised on the capabilities of the doctor; patients trust that their doctor is competent and will exercise good judgment in respect of their care. The competency involves putting to good use the skills of the profession, which includes using the information obtained in confidence appropriately and guarding it to the exclusion of others. However, it is not only the competency of others that motivates trust; that would be mere reliability. As we shall see in the final chapter, trust involves not only the expectation that the other is reliable, but also that she honours the trust placed in her out of moral commitment.

In all confidential relationships trust is reciprocal. It is not only the confidante that must be trustworthy, but the one that confides must be trusted that she is disclosing truthful and accurate information. This is essential in all facets of healthcare. Physicians, researchers, and health institutions trust that the information they receive from individuals is mostly accurate, otherwise the institution of medicine would cease to function effectively. Moreover, physicians and researchers trust that patients and subjects place trust in them.

As a corollary to trust, we can add fidelity as a basic element of confidentiality, since without assurances of the confidante's faithfulness and loyalty the patient or research subject would have little reason to trust. As Baier notes, "fidelity is certainly the

[22] O'Neill, p. 17

virtue of those who do not let down others when they have encouraged them to trust,..."[23] Lasky and Riva claim that fidelity is one of two primary principles that underlie confidentiality (the other being autonomy).[24]

Many theorists perceive autonomy, or the preservation of autonomy as an important element underpinning confidentiality. Yeo and Brook maintain that it is the *foundation* of the 'traditional' view of confidentiality,[25] similarly Cordess calls it the *basis* for a deontological approach to confidentiality[26], and Lasky and Riva assert that it is a *primary component* of confidentiality, "based on the respect for the client's ability to make reasonable choices about what he or she discloses and how that disclosure impacts his or her life."[27] This perception, however, is somewhat inaccurate. Confidentiality may be valuable for protecting autonomy, but this says something about its purpose or function, not about its constitutive features.[28] If we consider for a moment the other key elements of confidentiality that we have identified as structuring the concept– relationality, duty, trust, and fidelity – autonomy, as an individualist concept, fits poorly with the other elements which are largely relational. That is not to say that autonomy is absent from the notion of confidentiality, only that it is not a central element and thus has a less significant role.[29] Let us examine why this is the case.

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[23] A. Baier, *Moral Prejudices* (Cambridge, Massachusetts : Harvard University Press, 1994), p. 167.

[24] Lasky and Riva, p.456.

[25] Yeo and Brook, p. 89.

[26] Cordess, p. 26.

[27] Lasky and Riva, p. 457.

[28] We can distinguish between 'X' and why 'X' is valuable.

[29] Why autonomy cannot be a central ethical principle in the notion of confidentiality is explored below in assessing the 'traditional' view of confidentiality.

There is an element of vulnerability implicit in the notion of confidentiality. The vulnerability is manifest in the patient or research subject who engages in self-disclosure and is exposed to others. It is also expressed in the extent that one lacks control over the use and disclosure of the information divulged. For this very reason you must place trust in the practitioner; you must trust that she will not disclose your personal information willy nilly, and will not abuse it by using it in ways which you would disapprove of. For if you had control over your own information and were not vulnerable in this way, there would be no need to trust. Moreover, there is the special vulnerability that obtains from the inequality in the doctor-patient or researcher-subject relationship. In a very real sense, the patient or subject is at the mercy of the health professional. Trust is the primary element that sustains the confidential relationship, and the very notion of trust implies vulnerability. According to Baier, "to understand the moral risks of trust, it is important to see the special sort of vulnerability it introduces…The special vulnerability which trust involves is vulnerability to not yet noticed harm, or to disguised ill will."[30]

If we accept that trust is a central feature of confidentiality, and that trust presupposes vulnerability on the part of the subject, then we can see how the role of autonomy as a defining conceptual feature is limited. The subject does indeed exercise autonomy by choosing who to confide in – although in some research contexts this option is unavailable and autonomy is further restricted (we have to be mindful of context). Further, the placing of confidence in the researcher is not so much an act of attempting to control one's information (through surrogacy), as it is an act of trust compelled by

[30] Baier, p.104.

vulnerability. The confidential relationship can protect the subject's autonomy if confidence is respected –by ensuring that the information is used appropriately, is held to the exclusion of others, and so forth. Yet this shows that autonomy is a product, rather than an ingredient, of confidentiality. One might argue that in some sense, the subject retains control over his information by selecting a trustee to protect it[31] –but this way of analyzing it is plausible only to the extent that the subject and trustee are known to each other, i.e. have a direct relationship. Again, context is crucial. For most of observational research, the researcher and subject remain unknown to one another, thus the aspect of autonomy and control referred to is minimal, if not absent. Confidentiality can serve to protect autonomy (among other goods). However, autonomy as an individualist concept is closely aligned with privacy, whereas confidentiality as a relational concept is tied to trust. When we speak of confidentiality we are inclined to speak of trust, not autonomy.

3.1.3 On Being Distinct from Privacy

Confidentiality and privacy are closely related concepts and can overlap in the research context. This has often resulted in the conflation of the two, and confidentiality is sometimes misunderstood as an instantiation of privacy[32] or as a contractual form of it.[33] This is of course misleading, since having information remain private is not the same as having it remain confidential. Privacy implies that the information has not been viewed, that it is not yet known by others. In the context of research, I can say that my

[31] Presumably because the trustee will be familiar with the subject's expectations regarding how the information should be handled.

[32] Koggel, p.5.

[33] The Collection of Historical and Contemporary Census Data and Materials, United Kingdom. Available: http://www.chcc.ac.uk/overview/faq9/q1.html

information is truly private if it has not been accessed. Yeo and Brook assert that "privacy concerns the subject of information and his or her rights or interests with respect to whether others come into possession of that information and if so, who and under what circumstances."[34] Confidentiality implies that the information is already known by some other, it has already been shared and is private insofar as it is not openly disclosed, but it is no longer private *qua* private –someone knows it. Note:

> "Confidentiality concerns anyone who has possession of such information and his or her duties in connection with respect to sharing or not sharing that information with third parties."[35]

Anita Allen remarks,

> "Confidentiality is achieved where designated information is not disseminated beyond a community of authorized knowers."[36]

If we consider the trajectory of information flow in research from the point of acquisition to disclosure, a privacy breach occurs at the level of initial access, as when an unauthorized person views a health record. A breach of confidence, however, takes place further downstream where the information is already known, as when it is wrongfully disclosed or used. A breach of confidence involves a breach of privacy, additionally it can also include the inappropriate use of the information resulting in harm to individuals

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[34] Yeo and Brook, p.87.

[35] Ibid.

[36] A. Allen, p.24. This point about 'authorized knowers' is relevant for health research. In Ontario's health privacy legislation, the Personal Health Information Protection Act (PHIPA), 2004, the corresponding term of reference is 'circle of care'. Ontario's Privacy Commissioner, Ann Cavoukian states: "The "circle of care" is not a defined term under PHIPA. It is a term of reference used to describe health information custodians and their authorized agents who are permitted to rely on an individual's implied consent when collecting, using, disclosing or handling personal health information for the purpose of providing direct health care." Since researchers are not involved in providing care, they fall outside the circle of care (and hence the circle of knowers). Whereas those inside the circle can access, use and disclose information based on implied consent, researchers need to obtain express consent, or be granted a waiver of consent by a Research Ethics Board to access, use and disclose information for research.

and communities, as when it is manipulated in the ways outlined in chapter one. A breach of privacy involves wrongful disclosure, not misuse. A misuse of information resonates with a breach of confidence because what is entrusted in confiding the information is that, i) it not be circulated further – at least not beyond anyone approved by the individual, and that ii) it is used in a way consistent with the person's expectations. Thus privacy is concerned with access, and confidentiality is concerned with use and disclosure. This is consonant with Beauchamp and Childress's analysis in their highly influential *Principles of Biomedical Ethics.* They claim that privacy and confidentiality can be distinguished in terms of how each is violated. "Privacy is violated when an unauthorized person gains access to another person's private information, whereas confidentiality is violated when someone discloses private information about a person to another person without the first person's consent."[37] It also explains what motivates the customary assurances of the maintenance of '*privacy and confidentiality*' of our personal information in research – we are covered if we have both. Of the two, confidentiality is the pivotal concept for observational health research, since the key concern rests with the use of the information and its further disclosure.

Privacy is considered the broader concept, generally "covering a diverse set of legal and philosophical issues ranging from the debate on abortion to issues raised in the modern day context of electronic surveillance."[38] Confidentiality, it is claimed, is not usefully conceived as a concept that invites 'application across the board'. According to

[37] T. Deshefy-Longhi et al, "Privacy and Confidentiality Issues in Primary Care:Views of Advanced Practice Nurses and Their Patients", *Nursing Ethics* 2004;11(4), p. 380.

[38] Koggel et al, p.1.

Koggel et al, confidentiality has application in specific social practices and refers to kinds of relationships that are highly context-dependent and context-specific.[39] The relational aspect of confidentiality also distinguishes it from privacy. Confidentiality is a duty that arises from the nature of the relationship, and maintaining confidentiality protects the privacy interest as much as it protects the relationship. To speak of confidentiality is to say something about the relationship, the individuals involved, and the nature of the information. Habiba and Evans claim that it can also refer to the means by which confidentiality is achieved, so that confidentiality tells us something about the 'what, who, and how'.[40]

In contrast, privacy is thought to be a right, and no relationship is necessary to establish it. It may be contested that the relational aspect is not unique to confidentiality. One might argue that having a right implies that someone has a corresponding duty, and this dynamic makes privacy relational in the same way. However, the relationality inherent in the two concepts is not analogous. First, one can distinguish between a 'relation' and a 'relationship'. A relation is an abstraction, a characteristic that holds between two entities and it need not be of any moral significance, e.g. concepts in mathematics, my relation with respect to the sidewalk, i.e. that I am standing on it. Whereas a relationship is a relation that holds between people and thus is always morally significant. The nature of a relationship is defined by a common and often implicit understanding between the relevant parties as to the significance of the relationship, e.g. whether it is personal, impersonal, intimate, casual, professional, etc… Second, in

[39] Ibid.
[40] Habiba and Evans, p. 567.

confidentiality, the relationship is prior to any duties that follow from it. It is the relationship itself that generates the duty. With respect to privacy, a relation, and not a relationship, is established when the right is met with the corresponding duty on the part of someone. It is compliance with the duty that gives rise to the relation, and not the other way around.

The moral significance of the difference is discernible when we consider the nature of the information involved, the nature of the expectations, and the level of trust required to sustain (a relation of) privacy versus a relationship of confidentiality. According to Yeo and Brook, "To say that information is private is to say something primarily in relation to the subject of the information; to say that information is confidential is to say something primarily in relation to someone other than the subject to whom the information has been revealed". [41] There is an interesting difference in the characterization of the information that results from situating it in a fiduciary relationship. In the case of privacy, the information itself may have the quality of being 'private', i.e. it is highly sensitive, it is a secret, etc… To speak of private information is to qualify it and say something about its nature, independently of how it is perceived, treated or handled. It may turn out that the information is not private in an intrinsic sense, e.g. one's gender, which is in plain view of others, but because privacy speaks to the subject of the information, there is always the possibility that the information has the property of being 'private' in that intrinsic way. That feature of being 'intrinsically' private is true of the information whether or not the information is ever shared with anyone. We can say of the

[41] Yeo and Brook, p. 87

information that it is 'private' whether or not it has been maintained confidential. For example, as a matter of social convention, having a mistress is a private matter, thus information about illicit relationships is private, independently of whether that information is disclosed or not. If a scandal breaks out and the information becomes widely known, we can say that private information has been publicized, but it does not alter the nature of the information itself.

Confidential information on the other hand, is primarily confidential because of how it is handled between two or more people. Confidentiality is not a property of the information. Information is regarded as confidential not as a result of some intrinsic feature about its nature, but as a result of being held to the exclusion of others outside of the confidential relationship. Habiba and Evans claim, "whether a piece of information is to be regarded or held as confidential depends not on the nature of the data but upon the circumstances under which it is conveyed, to which the identities of the agents, and the time and place in question, are relevant."[42] For example, ordinary activities such as the planning of a surprise party may be regarded as confidential because of how the persons involved regard and treat the information. The details of a surprise party are not 'private' in the intrinsic sense that one's HIV status is, though it can be regarded similarly as confidential information. For information to be considered confidential information it must be agreed between two or more individuals that it will be held confidential to the exclusion of other specified or non-specified individuals;[43] whereas I can myself decide that some information, e.g. having a mole on my right arm, is private independently of

[42]Habiba and Evans, p.568.
[43] Ibid.

whether anyone else agrees it is. This also illuminates the way in which the relational aspect of a confidential relationship is a defining feature of confidentiality. In healthcare, we can expect some information to be at once private and confidential.

In a relationship, the expectation of confidentiality on the part of the person who has confided is high. A confidence breach would damage the interests of the one who has confided, as well as the relationship, thereby also harming the interests of the confidante. A breach of confidence is at the same time a breach of trust, because of failed expectations.

In contrast, one may have a high expectation of privacy but it is not necessarily directed towards a specified other. One might say that privacy belongs to the individual, and holds between the individual and the world.[44] In the absence of a relationship, there is no one I can point to and hold accountable to my expectation. If I am let down, I will feel disappointment, perhaps anger, and I am harmed as such, but there is no relationship on the whole that is damaged. In respect of trust, evidently we must invest trust in all sorts of relations that are not counted as relationships. As Govier remarks, "trust is implicit in our daily lives and social world".[45] However, trust is the basis for relationships and not for relations. The role of trust for the latter is incidental and not integral. We do indeed trust that someone will respect our privacy, but that trust is not

[44] J.N. Catudal, "Seeking a Clearer Understanding of 'Privacy' and 'Confidentiality'. Available: http://www.southernct.edu/organizations/rccs/resources/research/comp. Accessed: 10 Oct 2007

[45] T. Govier, *Social Trust and Human Communities* (Montreal & Kingston: McGill-Queen's University Press, 1997), p. 3.

required to sustain the relation, moreover, that trust[46] is of a different character than the kind we invest in actual relationships.

There is another important feature that conceptually distinguishes confidentiality from privacy, which we have already touched upon –the role of autonomy. We saw in chapter two that autonomy plays a vital role in the defense of an individual right of privacy, often used as the grounds for justification of such a right.[47] In contrast, our earlier analysis showed that autonomy is less significant for the principle of confidentiality. Confidentiality is premised on a relationship of trust and vulnerability. The vulnerability is magnified in relationships of unequal power, e.g. the physician-patient and researcher-subject relationship. Consider the therapeutic context, where the patient is compelled to disclose intimate and personal details about herself if she wishes to obtain the benefit of treatment. It is only with the assurance of confidentiality that she risks such an undertaking, and because she is vulnerable and exposed, she must trust the physician will respect the confidentiality of her information. In this context, autonomy is less important than trust and fidelity, although autonomy has a role in that it may be willingly relinquished in favour of a desirable competing good –healthcare. Theorists of the liberal persuasion might argue against a dismissal of autonomy as less significant than other principles, claiming that confidentiality is protective of autonomy.[48] It is true that confidentiality can be protective of autonomy, however, this mistakes function for form;

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[46] Govier describes this type of trust as 'scatter trust', the kind of trust that is placed in strangers or persons we don't know very well. It is distinguishable from the trust we place in those with whom we have relationships in that it is not informed by previous experience or heavy expectations.

[47] Richard F. Hixson, *Privacy in a Public Society: Human Rights in Conflict* (New York: Oxford University Press, 1987), p. 96.

[48] Yeo and Brook, p. 89. See also Lasky and Riva, "Confidentiality and Privileged Communication in Group Psychotherapy" in *International Journal of Group Psychotherapy* 2006; 56(4), p. 456.

the conceptual content of confidentiality points primarily towards the elements of trust, vulnerability, fidelity and relationality.[49]

In summary, confidentiality is distinguishable from privacy in several important ways. First, at the level of information handling, a privacy breach occurs at the point of access in simply coming to know the information, whereas confidentiality implies that the information is known to the parties of the confidential relationship, thus a breach occurs through inappropriate disclosure or misuse of the information. Second, confidentiality is grounded in relationships whereas privacy is not and as a result the role of trust and expectations are more pronounced in confidential relationships. Third, information may be characterized as confidential as a result of its treatment within a determined relationship, and not because being confidential is an intrinsic property of it in the way that being 'private' is a quality of certain sensitive information. And finally, autonomy is pivotal to the notion of privacy, serving as the very grounds for its justification in many philosophical perspectives, while autonomy plays a less prominent role in the conceptual framework of confidentiality.

Having now examined the nature of confidentiality and how it is distinguishable from privacy, we can now consider the foundations for its moral framework. In choosing a moral framework to conceptualize confidentiality we must be mindful of the context we are dealing with, the values reflected, the interests protected, and how these cohere for a suitable model of application.

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[49] There are other moral precepts such as care, beneficence, and accountability that are relevant to confidentiality. For brevity, I have chosen to highlight the primary ones.

3.2 Moral Foundations: Two Views

Confidentiality can usefully reframe many of the concerns that revolve around the privacy issue in health research because it is not restricted to protecting privacy; it is broad enough to capture other interests. This claim, however, presupposes a particular conception of confidentiality. In what follows I shall examine two dominant conceptions of confidentiality as presented by Yeo and Brook, the 'traditional' and 'emergent' views, and focus on the latter because of its greater relevance to the present context.

According to Yeo and Brook, the traditional and emergent views of confidentiality are grounded in the two leading strands of normative ethics, i.e. deontology and utilitarianism respectively, and they see the development in moving from a rights-based approach of confidentiality to a consequentialist one as detrimental to the individual. While their analysis of the moral foundations of the two views of confidentiality mapped onto deontology and utilitarianism is correct, I do not believe these are mutually exclusive distinctions. There is no reason to think the traditional view grounded in deontology entirely dismisses consequentialist considerations. Moreover, and more importantly for our analysis, the emergent view of confidentiality grounded in consequentialism is not incompatible with fundamental deontic principles of respect for persons and dignity. Furthermore, it is this nuanced 'emergent' view of confidentiality that is appropriate for the research context under consideration since it is capable of accounting for the protection of many relevant interests. Although Yeo and Brook's account is situated in the therapeutic context of psychotherapy, their analysis is informative and with some qualification can be considered and extended to the research context. In particular, their

analysis highlights the conceptual shift in confidentiality as a consequence of developments in information technology which are specifically relevant to the context we are dealing with.

3.2.1 The 'Traditional' View

According to Yeo and Brook, there is an old way of thinking about confidentiality which is founded on basic deontological principles. On the 'traditional' view, confidentiality is rooted in the autonomy and dignity of the individual and is concerned with the individual's "right to keep information about oneself private if one so chooses".[50] On this conception, information about an individual can be disclosed only under very specific conditions. In the therapeutic context, without consent, disclosure is permissible to avert harm or to prevent a serious miscarriage of justice. In the research context, disclosure outside the group of authorized knowers unconditionally requires consent from the individual. As Yeo and Brook remark, "the question of who has the right to release or consent to release information is fundamental".[51] This right falls to the individual (except where there are strong countervailing reasons as noted above), therefore consent is at least a necessary condition for justified disclosure.[52] This is because the requirement of consent is seen as capable of preserving the autonomy of the individual where a breach of confidentiality is necessary. As Faden and Beauchamp note, "respect for autonomy is the most frequently mentioned moral principle in the literature on informed consent, as a

[50] Yeo and Brook, p. 88.
[51] Ibid.
[52] Ibid, p. 88.

principle rooted in the liberal Western tradition of the importance of individual freedom and choice,..."[53] Indeed, Yeo and Brook claim that a strict liberal defense of confidentiality implies "that those affected have control over matters of concern to them. When these are matters of information, to have such control entails that information can be released only with the consent, in fact the informed consent, of the person concerned."[54]

The centrality of consent in the traditional conception of confidentiality poses a problem for its adoption in the observational research context. First, it is skewed for the therapeutic context. Recall that the vast majority of observational research is allowed to proceed without consent, thus a model of confidentiality requiring consent for each disclosure of information would find all disclosures in the course of research unjustified breaches of confidentiality. Second, as our discussion in chapter two illustrates, informed consent is fraught with some theoretical and practical limitations, as such there is some question about its effectiveness in safeguarding autonomy.[55]

The bulk of discussions pertaining to confidentiality tend to focus on the therapeutic context. This is primarily because confidentiality is a principle that is meaningful and functional within relationships. In research, confidentiality is notable when there is a direct relationship between the researcher and subject, as in the undertaking of clinical trials or genetic studies. As such, analyses of confidentiality are informed by the values inherent in these well-defined relationships. Autonomy is a

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[53] R. Faden and T. Beauchamp, *A History and Theory of Informed Consent* (Oxford: Oxford University Press, 1986), p.7.

[54] Yeo and Brook, p. 89.

[55] Faden and Beauchamp(1986), O'Neill (2002), and Lysaught (2004).

principle held to be of central value. Respect for the autonomy of patients and research subjects is codified in practice and legal norms and is the primary constraint limiting the actions of others. According to Faden and Beauchamp, "the moral demand that we respect the autonomy of persons can be formulated as a *principle of respect for autonomy*"[56][original emphasis], where autonomy implies capacity for self-determination and the right to choose and make decisions for oneself based on personal values and beliefs.[57] A model of confidentiality premised on respect for autonomy, and thus implying consent, is well-suited for the care-provider and patient relationship, where treatment is given only with informed consent and patient satisfaction is of paramount importance.[58]

However, such a model is inconsistent with the reality of observational health research where participants do not have a direct relationship with the researcher, are unaware of their participation and thus have no opportunity to meaningfully act on their wishes or exercise their choices. An autonomy-based model of confidentiality is thus ill suited to apply to the object of our analysis.

A view of confidentiality rooted in autonomy may even be problematic in the therapeutic context. Yeo and Brook argue that the traditional view which prizes the liberal values of autonomy and dignity winds up having to be modified or supplemented in debates in psychotherapy.[59] This distortion is needed to accommodate the problem of consent, (which we acknowledged is the chief manner in which respect for autonomy

[56] Faden and Beauchamp, p. 8.
[57] Ibid.
[58] O'Neill, p. 18.
[59] Yeo and Brook, p.89.

materializes), and to address the *harm principle*[60] [original emphasis]. Yeo and Brook claim that "consent is itself a vexed notion in psychotherapy where transference, primitive regressions, and so on may be taking place, in practice the therapist takes the patient's place and makes the decision as to when, if ever, circumstances are sufficiently severe to warrant a breach of confidentiality."[61] The challenges of transference and/or regression lead therapists to believe that patients are incapable of making good judgments for themselves, thus they undertake to make decisions on their behalf, "deciding what information gets released, to whom, and in what form (usually without the patient consenting to the therapist assuming this role)."[62] We might be cautious here in extending the consent problem encountered in psychotherapy to other contexts where emotional and cognitive factors are less prominent. However, the example is useful in illuminating the responsibility taken on by those who are confided in, who must in such cases determine their obligations with respect to confidentiality by balancing competing interests (those of the patient/subject, third parties, dignity, equality, etc…) rather than by reference to the autonomous decisions of those confiding in them. Neither the psychotherapy patient nor the subject of observational research is in a position to change the outcome, and thus they are similarly situated in this regard. Recall that O'Neill sees this kind of paternalism as probably of relief to most patients, since through ignorance, injury or illness, most patients are simply too vulnerable to muster sufficient autonomy to make these decisions for themselves. Taken together, these arguments lend support to

[60] Ibid, p. 90.
[61] Ibid.
[62] Ibid.

our earlier assertion that autonomy is of less significance to confidentiality than the principles of trust and fidelity, rendering questionable the viability of any conception that is rooted in autonomy.

A second reason why care-providers depart from pure liberalism is conflict with the 'harm principle'. Traditional liberalism accepts that fundamental principles of autonomy and justice need to be balanced. The preservation of autonomy sets strong limits on the right of the state and others to intervene in the lives of individuals,[63] however most liberal theorists recognize that individual autonomy can be infringed upon when the safety of others is at stake. Mill argued "that the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."[64] Many therapists, however, are divided with respect to the harm principle.[65] As evidenced by *Tarasoff v. Regents*, there is little consensus over whether a patient's right to confidentiality can be legitimately breached in the interests of a third party, even where those interests are particularly compelling, such as the risk to one's life. Kipnis argues tenaciously for unqualified confidentiality, claiming that it promotes more effective therapeutic alliances with patients, results in better outcomes, and on the whole is most likely to prevent serious harm to a larger number of people.[66] His argument appreciates that preservation of confidentiality in individual instances can be an instrument to securing wider public goods. So what we have is, as Yeo and Brook astutely point out, "two values fundamental even within liberal theory, namely,

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[63] Yeo and Brook, p. 89.
[64] J.S. Mill, *On Liberty* (Indianapolis: Hackett Publishing Company, Inc.,1978), p. 9.
[65] Yeo and Brook, p.91.
[66] Kipnis, p. 17.

preserving the confidentiality of the patient and protecting others or punishing a perpetrator are at war and there is no easy way within an autonomy-based approach to confidentiality to reconcile them."[67] This last point illustrates how even the deontological based model of confidentiality does not dismiss consequentialist concerns.

We can see that the traditional view of confidentiality which is rooted in the liberal values of autonomy and dignity is an ill-suited conception for the research context and may be limited even for the therapeutic context. It is also of interest that this conception is remarkably similar, and runs parallel to, the liberal privacy paradigm, illustrating how easily the two concepts can be conflated. Both offer individualist-centered accounts, and with respect to confidentiality, we might have anticipated how it would be a poor fit.

I will now turn my attention to the 'emergent' view of confidentiality and assess whether this conception properly captures the notion of confidentiality that is suitable in observational health research.

3.2.2 The 'Emergent' View

Yeo and Brook correctly assert that there has been a shift in how people think about confidentiality. This shift has been prompted by two significant developments in healthcare: the move towards computerization and the 'bottomless demands for more health information'.[68] They note, "in digital form, information can be more readily and inexpensively searched, reproduced, indexed, collated, aggregated, and shared. This

[67] Yeo and Brook, p.92.
[68] Ibid, p.85.

considerably enhances its usefulness or value for a variety of purposes, including financial and social policy purposes."[69] Furthermore, accountability, audit, research, quality assurance, efficiency, cost-effectiveness, and evidence-based medicine are 'information hungry' objectives.[70] They are also considered important social objectives. With the increasing need for ever more information, and with advanced technology available to facilitate its manipulation and exchange, confidentiality is continuously under threat. The emergent view of confidentiality seeks to protect and promote interests, which according to Yeo and Brook, are synonymous with the important social objectives. To advance these interests, theorists have conceptualized confidentiality in a way that considerably widens the circle of authorized knowers of information, and attempts to morally justify confidentiality breaches. The emergent view of confidentiality manifests a utilitarian philosophy.

This emergent view of confidentiality is primarily concerned with achieving broad social objectives and accruing the benefits of informed social policy.[71] These objectives are loosely organized around research, population health, and economic efficiency, and are deemed collective interests. Thus "confidentiality is viewed as a matter of protecting or prompting patients' *interests*, not a matter of rights of the patient or duties of the therapist"[72] [original emphasis]. Yeo and Brook further maintain that, "on this new view, the question of under what conditions a patient's interests are protected by deleting identity, aggregation, and so on, is not necessarily a matter for the patient or even the

[69] Ibid.
[70] Ibid.
[71] Ibid, p. 86.
[72] Ibid, p. 88.

therapist to decide. This question can legitimately be decided by third parties; for example, insurance companies, policy planners, legislators, or the courts."[73]

An immediate implication of construing confidentiality in this way is that it widens the circle of the confidential relationship considerably. Where previously the confidential relationship was restricted to the person who confides and those she confides in directly –the legitimate circle of knowers—we now see an expansion of that circle to accommodate third parties.

Confidentiality framed around the idea of interests, and particularly inclusive of collective interests, is clearly not confined to protecting the privacy interest of the patient. There are various other interests worth protecting: the interests of care-providers, institutions, and society at large. These interests are not necessarily at odds with each other and can be congruent, but the key question the emerging view asks is: "What interest does a patient or therapist have in keeping something confidential? It is those interests that we should be protecting, not autonomy or the ability to choose as such."[74] Notice that the question asks 'what interest does a patient *or* therapist have in keeping something confidential': the disjunctive is indicative that the interests of the patient do not trump any other interests. If anything, they are on the same footing with the interests of the care-provider. This remarkable shift from the individualist paradigm suggests two possibilities: i) a complete rejection of individualism, and/or ii) the assumption that individual interests are closely aligned with other, broader social interests. I suspect it is some combination of both. There is likely to be rejection of wholesale individualism in

[73] Ibid.
[74] Ibid, p. 93.

any account that shows deference to community interests. As well, one can argue that there is no reason to believe *a priori* that individual interests are incompatible with social interests. This last point merits closer examination. What interests in particular are proponents of the emerging view wanting to protect? We can identify two sets of interests: i) the interests of the individual patient and ii) the social interest. In terms of the interests of the patient, the focus tends to be on preventing harm, so proponents look to "protective measures such as de-identification of data, strict security rules, confidentiality contracts, prohibitions on using information to discriminate against people, and assurances that information will not be used for administrative decisions against a person."[75] The social interest is primarily concerned with the use of information for purposes unrelated to the care of the patient. The ethically significant feature of the emergent view is that where there are important social objectives to be met through the use of the information in question, and use of the information does not result in harm to the individual, then the use of the information is not considered a breach of confidentiality – whether or not consent has been given.[76] Yeo and Brook note that proponents of this view construe harm narrowly, and ignore the harm that can be done to 'abstract and subtle things' such as autonomy and dignity.[77]

To recap, both the traditional and emergent views of confidentiality are concerned with limiting use and disclosure of information outside the approved circle of authorized

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[75] Ibid, p. 93.

[76] Ibid, p. 94. Yeo and Brook specify consent from either the patient or the therapist because their discussion is situated in psychotherapy. Where I refer to obtaining or providing consent, I am implying consent from the patient or the research subject.

[77] Ibid. This is a crucial point, which I address in my revised model of the emergent view of confidentiality.

knowers. The autonomy-centered traditional view grounds those limits in deontological reasons of respect for the autonomy and dignity of the individual. The social objectives[78] (or emergent) view is grounded in the utilitarian calculus of what will maximize social interests, where those interests include preventing harm to the individual. In practical terms, the difference cashes out in the circumstances under which it is permissible to use and disclose information without individual consent: the traditional view does not permit use and disclosure without explicit consent, whereas the emergent view does – so long as the patient is not harmed in the process. The former considers disclosure without consent a breach of confidentiality, with some proponents viewing concurrence with disclosure as a breach nonetheless (justified breach). Whereas the latter does not consider a harmless disclosure in the absence of consent a breach of confidentiality at all; instead it is viewed as being consistent with the protection and promotion of interests.[79] As one might expect, governments, institutions and various third parties concerned with the business of achieving social objectives tend to favour the emergent view of confidentiality.[80]

The emergent view of confidentiality with its ability to capture individual *and* social interests is more aptly suited for the research context than the traditional view. And with its departure from radical individualism, it is a good starting place for a model of confidentiality that is aiming to capture communal interests. However, as it is, the model is ethically deficient. Yeo and Brook note its attempt to tease out 'some anemic notion of rights' by focusing on the prevention of harm to individuals. And we have to

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[78] At a later point in their discussion, Yeo and Brook adopt the terms 'autonomy' and 'social objectives' view to refer to the 'traditional' and 'emergent' views respectively.

[79] Ibid, p. 97.

[80] Ibid, p. 95.

ask: are basic deontic principles of respect for persons and dignity truly incompatible with the emergent conception of confidentiality? Do individual interests need to be narrowly prescribed as merely the prevention of harm in order to achieve social objectives? Furthermore, the emergent view is said to be focussed on social interests, but these social interests appear to be whatever interests the government and public institutions have. As presented, the model does not speak to the social interest that various communities and groups have in maintaining confidentiality collectively. For example, the stigma that attaches to mental health patients as a group. The limit on the use and disclosure of information is assessed on the harm that can befall the individual, and in this sense, the emergent model has not fully broken from the traditional model. Yeo and Brooks' account makes no mention of whether the emergent view is concerned with preventing harm to entire groups or communities of people, i.e. collective harm. Clearly, the emergent model needs some refinement.

In this chapter I have identified the conceptual elements of confidentiality and sought to distinguish it from privacy. The two concepts often overlap and can be conflated, but as the analysis showed, they are quite distinct. Privacy is individualist, while confidentiality is relational, and in this we find that individual autonomy figures more prominently in privacy, while trust is a defining feature of confidentiality. I also considered two moral frameworks for conceptualizing confidentiality in the observational research context: one deontological, the other utilitarian. Neither framework proved to be entirely satisfactory, although the consequentialist framework offered a promising start. In the next chapter I will attempt to revise the consequentialist framework and transform

it into a 'mixed' model of confidentiality that can account for individual and social interests without neglecting the deontic principle of respect for persons.

-- Chapter 5 --

The 'Broad' View of Confidentiality: Deontic-Consequentialism

The emergent social objectives model would be much improved if it were more inclusive on two fronts: i) account for a basic deontological principle, such as respect for persons; and ii) account for social interests that are broader than the objectives of research, such as the interest in trust. In what follows I will attempt to refine the social objectives model by suggesting how we might incorporate the principle of respect for persons into its consequentialist framework. In this deontic revision, the notion of interests is widened beyond the interest in avoiding harm to individuals, to include the interest in maintaining the dignity of individuals and groups whose information is used, thus recognizing the notion of collective interests. As a result of expanding the notion of interests, we see a corresponding expansion in the conception of harm, with the admittance of wrongs that can be characterized as 'symbolic' harms.

This revisionist model appreciates that the collective interests of the public *include* the social objectives of research (e.g. disease tracking) that are too often presented as being in conflict with the interest in privacy. These social interests presuppose broader social values that are worth protecting, such as charity, solidarity, and trust[1]. Individually and as a collective, there is an interest in the ability to be charitable and contribute to research without fear of being harmed; it is common enough to want to give gifts. For some, there is an interest in being in solidarity with the various groups in

[1]I will focus the analysis on trust. Charity and solidarity are important values and merit deeper consideration than can properly be given here. I leave their treatment for another occasion.

society that contribute to research, including the various 'disease' communities and the research community. And finally, there is an interest in having trustworthy institutions, so that at every turn one is not worried about being coerced or deceived. The interest in fostering and sustaining trust is of special importance in confidentiality and thus merits closer examination. We turn to it in the next chapter.

The reformed emergent model, what I shall call the 'deontic-consequentialist model', shows us that confidentiality is broader than the concern for individual privacy and is capable of capturing wider social interests. It is this broader view of confidentiality that can offer an adequate moral framework for observational health research.

This chapter will examine how we might account for the principle of respect for persons in our model of confidentiality. Respect for persons requires taking the interests of the subject into account, thus our model urges that information users be concerned with maintaining the dignity of subjects, as well as concerned with avoiding harm. Maintaining the dignity of subjects entails treating them as ends in themselves, which at a minimum requires recognizing subjects as persons and not merely as 'bits of data' to be used in research. Additionally, it requires the recognition that subjects can be harmed in non-tangible though symbolic ways when they are not respected as persons; failure to appreciate this is particularly grievous for those who are already in a vulnerable state independent of the research. If observational research is to continue in the absence of individual consent, it is essential to recognize the importance of confidentiality and appreciate the various interests it is capable of protecting when it is honoured.

5.1 Respect for Persons

How can we maintain respect for persons and preserve the dignity of individuals and communities in the unconsented-to use and disclosure of personal information to satisfy social objectives? If we could find a way to reconcile this aim, we would have a model of confidentiality that would be ethically satisfying to both research subjects and researchers. We might start by considering what it would mean in terms of a breach of confidentiality. The traditional deontological framework of confidentiality finds it necessary to obtain consent for information use and disclosure to preserve the autonomy of the individual. Without consent, use and disclosure is considered a breach of confidentiality. The consequentialist framework of the emergent view finds no need to obtain consent for information use and disclosure if the individual will not be harmed as a result of the research, and this is not considered a breach of confidentiality. What sort of framework is implied if you had a *justified* breach of confidentiality for unconsented use and disclosure of information? That is, a recognized breach, but one that was ethically acceptable on some moral grounding. Such a model would not require consent for information use and disclosure because it was acceptable on some combination of deontological and utilitarian moral principles; a sort of mixed deontology suggests itself.

I propose a deontic-consequentialist framework for a moral foundation of confidentiality in observational health research. We might call this the 'broad' conception of confidentiality because it is broad enough to import relevant individual interests from the traditional conception into the social objectives framework. This type of mixed conception which attempts to balance deontological and utilitarian moral

considerations is ideally suited for the research context. Observational health research is considered to be of minimal risk[2] since there is no contact with subjects and their privacy is observed through a spectrum of security measures, e.g. employing non-nominative data or reporting results in the aggregate. In some circumstances the social imperative can be pressing, such as studying a rapid infectious disease outbreak, e.g. SARS. In other less urgent situations the social objectives may still be sufficiently weighty to override the confidentiality of individuals. Thus we must be able to take into account utilitarian moral concerns. At the same time, we would be ethically remiss if we failed to protect the interests of subjects in the course of satisfying social objectives. A framework that is focused on interests, in particular the interests in avoiding harm and promoting the social good, while explicitly recognizing the respect that is owed to research subjects, is appropriate.

The traditional rights-based model of confidentiality emphasizes respect for autonomy. Our account takes *respect for persons* as the fundamental deontic principle. Some theorists believe that 'respect for persons' over time transformed into 'respect for autonomy' as autonomy gained prominence within the field of bioethics.[3] Lysaught carefully traces the intellectual archeology of this phenomenon, identifying the crucial turning point in 1979 with the release of the first edition of Beauchamp and Childress's

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[2] The standard of minimal risk is defined by the TCPS as follows: "if potential subjects can reasonably be expected to regard the probability and magnitude of possible harms implied by participation in the research to be no greater than those encountered by the subject in those aspects of his or her everyday life that relate to the research then the research can be regarded as within the range of minimal risk." [Article C1].

[3] M. T. Lysaught, "Respect: Or, How Respect for Persons Became Respect for Autonomy" (2004) 29:6 *Journal of Medicine and Philosophy* 665; and O'Neill (2002), p. 34-37.

influential *Principles of Biomedical Ethics.*[4] Prior to the *Principles*, respect for persons had functioned as the central tenet of ethical research involving human subjects; following the *Principles,* 'respect for autonomy' took on this role, where "respect for autonomous persons cashes out as informed consent".[5] According to Lysaught, one implication of this substitution is that "those with compromised autonomy are no longer protected by the canons of 'respect' but rather the less overriding canons of beneficence."[6] Moreover, taking note of the theoretical and practical limits of consent that were exposed in chapter two[7], I am motivated to re-instate the principle of *respect for persons* as the guiding deontic principle in our revised model of confidentiality.

Consider:

> "[T]o respect another means to regard her or him highly –to esteem, honor, value in his or her uniqueness or distinctiveness,…"[8]
>
> "[T]he phrase often entails a sense of deferring to the other, considering the other's interests and feelings, attending to his or her needs, looking out for the others well-being. Such deference may even require limiting or restricting ourselves…."[9]

Going back a little earlier in the historical trajectory, Lysaught finds Paul Ramsey's *The Patient as Person,* whose notion of respect for persons is informed by a strong Kantian ethic and grounded in the theological idea of convenant. Combined, these two distinct ideas are informative for our purposes. Ramsey was a theologian and he had in mind a

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[4] Ibid.
[5] Ibid, p. 668.
[6] Ibid, p. 665.
[7] Recall O'Neill's criticisms of informed consent. She argued that patients and subjects in medical practice were unable to exercise robust autonomy and subsequently failed to comprehend what was being offered through informed consent which is opaque. In some cases, it is impracticable to seek consent.
[8] Lysaught, p. 665.
[9] Ibid.

convenant between man and god; in our analysis we can substitute 'researcher' for 'god',[10] and the convenant is the duty of confidentiality.

> "Ramsey rooted his understanding of respect in what he believed is the fundamental nature of human relationality, namely covenant."[11]

> "[T]he practice of medicine is one such convenant. *Justice, fairness, righteousness, faithfulness, canons of loyalty,* the *sanctity* of life, *hesed, agape,* or *charity* are some of the names given to the moral quality of attitude and action owed to all men by any man who steps into convenant with another…"[12]

It is interesting that the canons of duty in Ramsey's convenant are remarkably similar to the values imminent in confidentiality, viz. faithfulness, loyalty, justice, charity. Lysaught notes that the 'principle of respect for persons' is not articulated on any page of the book, but Ramsey's Kantian sensibilities are reflected in an early passage, and elsewhere:

> "[W]e shall ask, what are the moral claims upon us in crucial medical situations and human relations in which some decision must be made about how to show respect for, protect, preserve, and honor the life of a fellow man?"[13]

While Ramsey did not specify a principle of respect for persons, Lysaught claims he understood his use of the term 'person' (invoked in the title of the opus) as suggesting Kant's dictum that persons are to be respected and treated as ends in themselves.[14]

Why should 'respect for persons' be a more suitable deontological grounding than 'respect for autonomy' in the duty of confidentiality? The former is a far more complex principle to instantiate, and as Yeo and Brook remarked, it is of the 'abstract and subtle'

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[10] No pun intended.
[11] Ibid, p. 672.
[12] Ibid. Lysaught quoting Ramsey.
[13] Ibid.
[14] Ibid.

kind and there is some question as to what action is required to demonstrate respect for persons; in contrast, the latter can supposedly be concretized by obtaining informed consent. We have already seen how attempting to secure 'respect for autonomy' through informed consent may not always be satisfactory. Let us examine why 'respect for persons' is of merit.

The notion of respect for persons is in many ways more encompassing than respect for autonomy. Respect for autonomy is narrowly concerned with respecting the capacity for self-determination that others have, so that those who lack this capacity or their autonomy is otherwise compromised (in the ways that O'Neill suggests) are at risk of *not* being respected in this way, e.g. children, the sick, and the mentally incapable. Yet all persons are equally deserving of respect. In respecting persons we acknowledge their worth and their dignity as persons, independently of their capabilities, qualities, and status. Having the respect of others is essential for our concept of selfhood, self-integrity and sense of worth. Human beings are relational beings; we define ourselves to some extent by how others relate to us. If we are routinely shown care and respect, we believe that we are worthy of care and respect. We are unlikely to find someone who is consistently devalued having a positive self-image and sense of worth; the sad experience of battered and abused women is a perfect illustration. As social beings we incorporate attitudes from the external world into our concept of selfhood. For this reason we are careful and selective about what we share with others. Exposing too much of ourselves, and we run the risk of ridicule or being judged unfairly. Nagel claims that, "the additional inner life that derives through internalization from civilization itself creates a

further need for selection of what will be exposed and what concealed and further demands of self-presentation"[15]. Nagel's argument is telling about how people construct themselves, and points to the importance of self-presentation. Others can perceive us in a variety of ways, but we selectively conceal and expose aspects of ourselves to represent the person we want them to see; this is the way in which self-presentation is essential for selfhood. Fundamentally, we care about what others think of us, and it reflects in the opinion we hold of ourselves. Thus we can distinguish at least two reasons for respecting persons: i) persons are deserving of respect; and ii) self-respect depends in some measure on the respect of others.

In Kantian terms, moral respect entails treating persons as ends in themselves and never merely as a means. This is a challenging moral requirement to uphold in the research environment, where the very purpose of research is to use human subjects for a determined end. In observational health research, there is a real danger of instrumentalising subjects owing to the anonymity that is pervasive in this type of research. Methods of de-identification that strip identifying variables from personal information (e.g. name and birthdate) to safeguard the privacy of individuals, at the same time threaten to strip personhood along with identity. This is quite ironic, given that the argument for anonymising data is to protect and respect the individual[16]; little thought is given to how anonymisation facilitates instrumentalism. Investigators use 'bits and pieces' of information from a variety of sources and this collection of data variables

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[15] Nagel (2002), p.5.

[16] Nourmeir, R. et al "Pseudonymization of Radiology Data for Research Purposes" (2007) 20:3 *Journal of Digital Imaging* 286.

leaves but a trace of the 'person'. There is a small chance of residual identification, and this is thought to be the challenge in terms of personal privacy, since "a combination of attributes may enable one to almost uniquely identify a patient by linking this information with a publicly available external source of information."[17] But there is another challenge in regards to treating subjects as ends and not merely as means: the challenge for the researcher is to see beyond the collection of 'data bits' and to recognize that there is a real person behind the data. Researchers need to appreciate that how the data is used and disclosed may come to affect a real person or a community. Moreover, in manipulating the data, researchers have the capacity to alter how individuals or communities are viewed, and in this way they affect self-presentation. In observational research subjects are not in the position to select what aspects about themselves will be concealed and exposed. Consider the earlier example of the study examining patterns of disintegration of the stomach lining: suppose that a connection is made with alcohol consumption and the research discloses that I am a borderline alcoholic. That is not how I want to be viewed. For the researcher, the anonymity of the data may not speak to a specific person; however, the data *is* about a person. The mere recognition of this fact is a moral imperative.

Earlier we noted that 'respect for persons' was abstract and subtle. In many situations, showing respect is simple enough, as in removing one's hat when entering someone's home. In the context of observational research, spelling out what action (or inaction) is required to show respect is much more difficult. Respect is fundamentally an

[17] Ibid, p. 286.

attitude, it is taking the interests of the subject into account, and where necessary limiting or restricting our actions to protect those interests. To recognize a subject as an end in himself is to recognize him as a person, and not merely as a collection of data. The attitude researchers need to adopt is the Nozickian perspective that "there are only individual people, different individual people with their own individual lives. Using one of these people for the benefit of others, uses him and benefits others....To use a person in this way does not sufficiently respect and take account of the fact that he is a separate person, that his is the only life he has."[18] Nozick speaks of the individual, but the sentiment he expresses extends to groups and communities studied in research. The basic point is that there are *real persons* living *real lives* and research has the capacity to affect those persons and their lives in myriad ways.[19]

To see the person behind the data is a reminder to researchers that use of the information is a privilege and not an entitlement. Recent policy developments that have tightened privacy rules for information use in research have left many researchers disgruntled and lamenting that 'research is grinding to a halt' –as if research were the imperative and not the well-being of people.[20] Thus the recognition that there are persons behind the information is important if attitudes will change. Since researchers have no contact with specifiable subjects, the idea of person is symbolic, much in the same way

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[18] Raz (1988), p. 145, quoting Nozick from *Anarchy, State and Utopia* (New York: Basic Books, 1974).

[19] The exception being deceased subjects, but even in such cases there is the capacity to affect the legacy of the deceased individual, and hence affect surviving family members.

[20] J. Kaiser, "Privacy Policies Take a Toll on Research, Survey Finds" (2007) 318 *Science* 1049; and C. Verity and A. Nicoll, "Consent, confidentiality and the threat to public health surveillance" (2002) 324 *British Medical Journal* 1210; and A.S. Gershon and J.V. Tu, "The effect of privacy legislation on observational research" (2008) 178:7 *Canadian Medical Association Journal* 871.

that Ramsey's use of the word 'person' was enough to evoke Kant's dictum. Moreover, recognizing data subjects as persons also recognizes their contribution to research. There has to be an explicit understanding that observational health research is human subject research, and not merely epidemiological, statistical or informational research. And lastly, there has to be a consciousness that acting from ethical principles that all can adopt is harmonious with research and not an impediment to it. Good ethics and good science go hand in hand.

5.2 Private, Public, Welfare and Ulterior Interests

In the social objectives model outlined by Yeo and Brook , confidentiality is framed in terms of interests. There are the interests of the subject that narrowly correspond to avoiding harm in the event of a disclosure; and there are the interests of society which include diverse social objectives concerned with research, quality assurance, disease surveillance, and a variety of other initiatives which advance the social good. The former may be construed as the private interests of the individual, while the latter are the public interests of society. Furthermore, the interests of the individual are equated with protecting individual privacy, where this is deemed necessary to avoid harms such as discrimination.[21] The tension between these two sets of interests can be understood in terms of the private/public dichotomy, which is now so familiar to us.

The social objectives model prioritizes social interests, such as public health and quality assurance, and in advancing these, looks for ways to accommodate the individual

[21] Yeo and Brook, p. 93.

interest in privacy. While the model appreciates that social interests can be advanced through confidentiality, it does not explicitly recognize a social interest (meaning a collective interest) in privacy, i.e. that whole communities can be harmed through disclosure; or that confidentiality protects relationships which promotes trust in research; or that individual interests may coincide with social objectives. A broader conception of confidentiality embraces a wider array of interests. Let us consider more carefully what we mean by interests, what those interests are, and how confidentiality is able to protect them.

In the first volume of *The Moral Limits of the Criminal Law* Joel Feinberg distinguishes between welfare interests and ulterior interests. A person's welfare interests can be characterized as interests "presumably of a kind shared by nearly all his fellows, in the necessary means to his more ultimate goals, whatever the latter may be, or later come to be."[22] These interests are the basic goods required for 'a man's well-being' and include such things as "physical health and vigor, the integrity and normal functioning of one's body, the absence of absorbing pain and suffering or grotesque disfigurement, minimal intellectual acuity, emotional stability, the absence of groundless anxieties and resentments,…." and so on, but these goods do not constitute the whole of well-being. Complete well-being will include ulterior interests, which derive from welfare interests. That is, having one's welfare interests intact will enable the pursuit of ulterior interests, which are thought to be things like "achieving high political office, successfully raising a

[22] J. Feinberg, *The Moral Limits of the Criminal Law Volume One: Harm to Others* (Oxford: Oxford University Press, 1984), p. 37.

family, achieving leisure for handicraft or sport, building a dream house, advancing a social cause, ameliorating human suffering…"[23] etc. On this account, welfare interests are prior to ulterior interests, for as Feinberg notes, when they are blocked or damaged, a person is harmed and unable to pursue his ulterior interests. In Feinberg's view, an invasion of a welfare interest harms the individual in the most serious way.[24]

On this understanding, individual privacy can be considered a welfare interest. And so can one's dignity and reputation, for all of these things contribute to the integrity of selfhood, and these are in Feinberg's words, "the most important interests a person has."[25] Whatever interest an individual has in health research and fair social policies that contribute to the delivery of good health care may be considered an ulterior interest.[26] If welfare interests are prior to, and necessary for, the attainment of ulterior interests, then the subversion of welfare interests for the sake of ulterior interests is nonsensical.

The idea of compromising an individual's confidentiality to satisfy research goals starts to look very much like the thwarting of a welfare interest for the sake of an ulterior interest. Were we wrong to dismiss the traditional deontological model of confidentiality that sought to protect welfare interests first and foremost? I do not believe that this is the case. Feinberg qualifies that welfare interests may be the most important, but at the same time "they are relatively trivial goods, necessary but grossly insufficient for a good

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[23] Ibid.
[24] Ibid.
[25] Ibid.
[26] Arguably something like health care is a welfare interest in the sense that being healthy is necessary for the pursuit of ulterior interests. However, the systems and policies that contribute to a well functioning health care system are not welfare interests per se (except perhaps in a derivative sense), and so appear to be more like ulterior interests.

life."[27] His classification of interests advances a strong liberal agenda and presupposes that what has been defined as a welfare interest is the same for everyone. Isn't it possible that in a different set of circumstances what passes for an ulterior interest may become a welfare interest (and vice versa)? Feinberg's account ignores the significance of context. He considers 'advancing a social cause' an ulterior interest, but where the social cause is the removal of a tyrannical dictator in a violence-plagued city, it shows us that it is a welfare interest of the people whose very survival depends on it.

Furthermore, Feinberg's distinction fails to consider the possibility that interests can be a matter of taste. From the perspective of a serious philanthropist and humanitarian, sacrificing what are deemed basic welfare interests for ulterior interests may be compatible with what that person sees as in their best interest: a life of selflessness. Mother Teresa may not have had much privacy, or the absence of anxieties, and her humble environment may not have relieved her of physical discomfort, but perhaps these were not goods that she considered fundamental to her welfare. From her perspective, a life of sacrifice and selflessness and the renunciation of welfare interests were more compatible with her well-being, in being who she was. Feinberg's account does not entertain the possibility of altruism and how it can disrupt the orderly classification of interests. Interests can be fuzzy; drawing clear boundaries between welfare and ulterior interests may prove unwise. Moreover, if health is a welfare interest, than the conflict of interests is not between a welfare and an ulterior interest, but between the welfare interests of an individual and those of many people (e.g. a group of persons afflicted by

[27] Ibid.

disease), so we need to consider those interests concurrently, not forego one in favour of the other.

5.2.1 Advancing Competing Interests

Feinberg may have foreseen some of these problems, and attempted to address them in terms of a potential conflict between *interests* and *wants*, questioning whether everything that can be said about interests can be explained in terms of wants or desires.[28] He resolves that there is indeed a very close connection between interests and wants, but the matter is complicated –and beyond the scope of our analysis.[29] For our purposes, we shall focus on Feinberg's elucidation of the 'harmonious advancement' of interests, since this is relevant for imagining how we can promote multiple interests that appear to be in conflict. According to Feinberg, there are three ways in which the 'harmonious advancement' of interests occurs:

1) "X promotes all of Jones's interests harmoniously by promoting all of Jones's interests, i.e. both welfare and ulterior interests, either equally or unequally

2) X promotes a particular interest of Jones's, or a set of such interests, without impairing any other of his interests

3) X promotes some of Jones's interests and impairs others, but the ones promoted are superior in some relevant way to those that are impaired, so that the result is a net gain for Jones on the whole."[30]

The 'harmonious advancement' of interests illuminates several possibilities for reconciling how different, and possibly competing interests, can be promoted without

[28] Ibid, p. 38
[29] For more on this, see Feinberg (1984), pages 38-45.
[30] Ibid, p. 39

harming the individual. My argument is that a broad understanding of confidentiality can account for and protect individual and social interests that roughly correspond to welfare and ulterior interests. Before we examine how this might be so, let us take stock of the pertinent interests of the subject of observational health research.[31]

1) The individual has an interest in privacy.

2) The person may also have a collective interest in group privacy, if she identifies with membership in a vulnerable community.

3) As a research subject she has an interest in being justly treated and respected, and in not being harmed (e.g. stigmatized, discriminated, etc…) through the inappropriate use or disclosure of her personal information.

4) She has in interest in contributing to research that can advance the quality of health care and in turn improve the quality of her life.

5) She has an interest in having access to trustworthy institutions staffed by trusted and skilled professionals.

6) Lastly, she has a fundamental interest in social justice, in living in a society whose policies are just and equitable, where benefits and burdens are fairly distributed.[32]

7) We might add that the individual has an interest in controlling how her information is used in research if it is shown that institutions and researchers cannot be trusted to use it ethically.

It is notable that several of the interests of the individual subject coincide with social interests that are usually portrayed as being at odds. Both the individual and society share an interest in advancing programs and policies that benefit citizens, particularly the most vulnerable. And both have an interest in having trustworthy institutions and officials,

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[31] This list is not exhaustive and I concede that there may be relevant interests I have omitted. I have presented those interests that are the common foci of discussion.

[32] The fair distribution of benefits and burdens does not imply that they are to be *equally* distributed between all members of a society. (e.g. taxation; to be fair, higher income earners pay more taxes while low-income earners pay lower taxes).

since without public trust civil institutions would collapse. As Trudy Govier remarks, trust is social capital.[33] Our list speaks predominantly to individual interests, some of which take as their objects collective goods; however, we have noted that there is a 'collective' interest in privacy, so it is useful to distinguish an individual interest from a collective one.

5.2.2. Individual and Collective Interests

F.A. Hayek describes a collective interest as the interest of a particular group.[34] For example, intravenous drug users as a group may have an interest in publicly funded clean needle exchange programs. That is not to say that individual drug users do not have this same interest, however, a collective interest is distinguishable from an individual interest to the extent that the interest is pertinent for the group *as a group*[35], and not solely for the individual. Consider that a needle exchange program might be set up at a group home for the destitute where several of the residents are struggling with addiction, where it may not be set up in an affluent neighbourhood where some local residents are also known to inject heroine. In the former case, the residents have a collective interest in having free access to clean needles; in the latter case, the individuals do not share this interest collectively. While all intravenous drug users have an interest in having access to clean needles, only the poor residents in the group home have an interest in obtaining free needles through an exchange program.

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[33] T. Govier. *Social Trust and Human Communities* (Montreal & Kingston: McGill-Queen's University Press, 1997), p. 150.

[34] F.A. Hayek, *Law, Legislation and Liberty, Vol 2.* (Chicago: Chicago University Press, 1978), p. 6.

[35] By virtue of some distinct feature that distinguishes one group from another.

Hayek notes:

> "[A] collective interest will become a general interest only insofar as all find that the satisfaction of collective interests of particular groups on the basis of some principle of reciprocity will mean for them a gain in excess of the burden they will have to bear. Though the desire for a particular collective good will be a common desire of those who benefit from it…"[36]

Of special importance in the context of research is recognizing the collective interest in privacy and giving some consideration to how it can be best protected. Both the traditional and emergent views of confidentiality narrowly construe the privacy interest from the perspective of the individual, failing to recognize that there is a collective interest in privacy from the perspective of particular communities, e.g. communities of individuals with sensitive health conditions, such as AIDS, mental illness, etc.., traditionally marginalized groups such as Aboriginal groups, visible minorities, ethnic minorities, and so forth.[37] A breach of individual privacy is regrettable, but it is not morally equivalent to a breach of confidentiality in which entire communities are potentially stigmatized.[38] The harm is significantly different both qualitatively and quantitatively. In epidemiological and population health studies, data is considered in the aggregate, so that any conclusions derived from the study apply simultaneously to individuals *and* groups, affecting even those members that were not participants. In the event of an inappropriate disclosure, *all* members of the revealed community are stigmatized. Insofar as entire groups or communities have a collective interest in privacy, this interest is better protected through the maintenance of confidentiality rather than

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[36] Hayek, p.6.

[38] I am grateful to E. Gedge for pointing this out.

individual privacy. As we have seen, confidentiality is founded on a trust relationship and acknowledges the vulnerability of the parties whose information is used. Since it is a compelling fiduciary duty, it is common enough for those who contribute their data to trust, and for those who are entrusted with the data to honour their obligation.[39]

5.2.3 Social Interests

Hayek noted that a collective interest will become a general (or social interest) to the extent that satisfying the collective interests of groups is worthwhile for all other members of society, i.e. that everyone stands to benefit from the protection of those interests. In this respect, privacy is a broader social interest and not just an interest of individuals or collective interest of select groups.[40] Inasmuch as we live in a pluralist society, it is possible for any member to identify with a variety of different groups, any of which can have a collective interest in privacy at a given time. These various collective interests in privacy together make it worthwhile to have a social interest in privacy.

Feinberg outlined three different ways in which interests are 'harmoniously' advanced. In each of those three cases the individual is not harmed, though in case two some interests fail to be promoted, and in case three some interests are actually impaired. If we submit that the unconsented use and/or disclosure of personal information in research is a justified breach of confidentiality, we can consider it as a harmonious advancement of interests of the third kind, where some interests are protected and

[39] This assumes that researchers are trustworthy. I will address this point in the next chapter.

[40] Recall Priscilla Regan's analysis of privacy in chapter two. She claimed that privacy was a broader social interest because i) privacy is a *common* value in that everyone values some degree of privacy; ii) it is a *public* value, essential to a democratic political system; iii) and it is a *collective* value in contemporary society where it is hard for any one person to have privacy without all persons having a similar minimum level of privacy.

and disclosure of information in research are ethically acceptable, and we are proposing a broad conception of confidentiality that considers such uses justified breaches of confidentiality. The crucial aspect of our context of analysis is that subjects in all likelihood are unaware that they are subjects of research. Those that discover that they are, and do not wish to be, have a legitimate grievance and can remedy it by informing the institution or the researcher that they wish to have their information removed from the study, for instance. However, at least some observational health research is legally mandated, e.g. public health surveillance studies, and subjects do not have the luxury of claiming that they do not wish to contribute –in much the same way that they cannot avoid paying taxes.

Putting these special public health cases aside, an individual that comes forward and declares that he does not wish to contribute his information to research has a right to withdraw it, and his decision should be respected. This does not contradict our claim that he receives a 'net gain' were he to remain a research subject. He benefits on the whole even if he fails to recognize it. Here it might be useful to distinguish between individual interests in collective goods and collective or social interests as we described above. Hayek describes collective goods as goods that "can be rendered only to all members of various groups."[42] Healthcare is a collective good, and the systems and processes that promote healthcare (e.g. health research) may also be characterized as collective goods. Applying this to our case, we can see that the individual may not have an *individual interest* in health research (though presumably he has an individual interest in healthcare),

[42] Hayek, p. 6.

but he does have a *social interest* in it, albeit one that he does not acknowledge.[43] To the extent that he has this social interest and taking account of all the other interests he has, these are best promoted through confidentiality in the present context, and thus on the whole he would benefit.

5.3 Setting Back Interests: Harms and Wrongs

In claiming that a broader set of interests can be protected through confidentiality, we concede that there is a corresponding expansion in potential harms when it is breached. It is important thus to assess the various ways in which individuals, communities, and society can be harmed through inappropriate uses and disclosure of information.

The multiplicity and magnitude of the ways in which data subjects can be harmed through disclosure should not be underestimated. The use, misuse, and abuse of information can result in stigma, discrimination, and loss of socio-economic goods. Additionally, data subjects can be harmed in subtler ways, by being ill-perceived or erroneously judged, and be subject to dignitary harms, a class of harms referred to as 'symbolic' harms.[44] Even where there is no tangible harm done, subjects can still be wronged. All of these things are setbacks to interests.

It is useful to begin by considering the meaning of harm, which, as Feinberg notes, is a 'vague' and 'ambiguous' term. He distinguishes between a 'harmed' condition and a 'harmful' condition, claiming that "a *harmed* condition of a person may or may not

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[43] Recall that a social interest is one that is worthwhile for all members of a given society.

[44] E.(Boetzkes) Gedge , "Symbolic Harm and Reproductive Practices" (2000) 3*Law and Medicine* 327.

also be a *harmful* condition, depending on whether it has itself the tendency to generate further harm."[45] And to illustrate, he offers the example of a blistered finger which is a harmed condition, but not harmful – unless it is on the hand of a concert pianist.[46] This subtle distinction is important and we will return to it later.

According to Feinberg, the term harm can be parsed out into three senses that correspond to general usage. The first he characterizes as a derivative sense, which is to say that anything can be harmed.[47] Here he is referring to objects, things in general which can be damaged, broken, spoiled, squashed, chipped, mutilated etc…, and they count as being harmed only to the extent that someone has an interest in these things remaining intact. "Quite clearly this is harm in a transferred sense; we don't feel aggrieved on behalf of windows or the tomatoes, nor are they objects or our sympathies. Rather our reference to their 'harm' is elliptical for the harm done to those who have interests in buildings or the crops,…"[48]. Therefore, things which are of interest to no one are merely broken or damaged, but not harmed in this derivative sense.[49]

The second sense of harm refers to "the thwarting, setting back, or defeating of an interest."[50] To have an interest, is to have a *stake* in something. We can say that one's interests are comprised of all of the things in which we have a stake, and from the discussion above, our primary interest is the harmonious advancement of the collection of

[45] Feinberg, p. 31
[46] Ibid.
[47] Ibid, p. 32.
[48] Ibid.
[49] Ibid, p. 33.
[50] Ibid.

miscellaneous interests that we have.[51] Interests can be promoted or defeated. Consider what Feinberg has to say about the thwarting of interests:

> "They can be blocked or defeated by events in impersonal nature or by plain bad luck. But can only be 'invaded' by human beings, either by myself, acting negligently or perversely, or by others, singly, or in groups and organizations. It is only when an interest is thwarted through an invasion by self or others, that its possessor is harmed....One person harms another in the present sense then by invading, and thereby thwarting or setting back, his interest. ...whether such an invasion has in fact set back an interest is whether that interest is in a worse condition than it would otherwise have been in had the invasion not occurred at all."[52]

Feinberg's use of the word 'invasion' is telling; it speaks to the moral weight of the wrongdoing. Coupled with the fact that only moral agents can 'invade' interests, it suggests ill intent or negligence on the part of the invader.

The third sense of harm is what we might call a 'wrong' and can be considered a distinct notion from harm.[53] According to Feinberg, "one person *wrongs* another when his indefensible (unjustifiable and inexcusable) conduct violates the other's right, and in all but certain very special cases such conduct will also invade the other's interest and thus be harmful..."[54] In those very special cases where a wrong is not a harm on balance to interests, Feinberg asserts that it is a harm to some extent, most probably an invasion of the interest in liberty. To illustrate, he recounts the tale of a broken promise, whereby a fluke, it turns into an advantage for the promisee. Though the person has not been harmed and now even stands to benefit from this 'wrong', Feinberg asserts that "this wrong violates a kind of interest of the 'victim's' liberty, that is, an interest in himself

[51] Ibid
[52] Ibid, p. 34.
[53] Ibid.
[54] Ibid.

tying down the future in a certain respect and determining through his own choice what is to happen."[55] Feinberg's interpretation seems sensible. The very notion of a wrong suggests something is morally incorrect, even if no tangible harm results.

5.3.1 Tangible Harms

Discussions of the ways in which subjects can be harmed in observational health research relate primarily to the wrongful setback or thwarting of interests, or the second sense of harm. Tangibly these harms amount to discrimination[56], as when one is denied health insurance or employment, resulting in loss to socio-economic goods; and stigma, that results from being identified as a particular 'category' of persons, e.g. obese, or member of an already stigmatized group, e.g. gay, HIV positive, or mentally ill.[57] Not to say anything of the erroneous and epistemically questionable inferences that can be drawn from data, and that may serve to inform health and social policies that can negatively impact entire communities, or at the very least, fail to be beneficial to them. Moreover, the use and disclosure of genetic and genomic information can compound harm by affecting relatives and ethnic populations in the ways described above. These sorts of harms interpreted from a consequentialist perspective have been widely documented and discussed. It is the concept of a 'wrong'—the third sense of harm—that we need to explore.

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[55] V. Launis, "Solidarity, Genetic Discrimination, and Insurance: A Defense of Weak Genetic Exceptionalism" (2003) 29:1 *Social Theory and Practice* 87

Ibid, p. 35

[56] Ibid.

[57] Launis (2003). See also H. Tavani, "Genomic research and data-mining technology: Implications for personal privacy and informed consent" (2004) 6 *Ethics and Information Technology* 15.

5.3.2 Harmless Wrong? Or Symbolic Harm?

The idea of a harmless wrongdoing does not figure in the moral framework of the emergent model of confidentiality presented by Yeo and Brook. Recall that on this account a breach of confidentiality for the sake of attaining social objectives is not considered a breach, irrespective of whether consent is obtained, if no harm to the individual results from the breach. However, in our proposed broader conception of confidentiality the notion of wrongs takes on renewed significance. Why should the unconsented use and disclosure of personal information in research count as a 'wrong' if no actual harm follows? The recognition of a harmless wrongdoing in breaching confidentiality for some justifiable aim is designed to capture the deontic principle of respect for persons. I suggested that researchers adopt the attitudinal posture of seeing themselves justifiably breaching confidentiality – though breaching it nonetheless—as an acknowledgment that there are persons behind the data and they deserve respect. Data is easy to manipulate, alter, and discredit, but not persons; researchers want to refrain from harming persons. My argument takes for granted that moral agents recognize the inviolability of persons and avoid morally offensive actions that would use others as merely means to an end.[58]

The very idea of a 'harmless' wrongdoing is a contradiction. Feinberg asserts that "there *can* be wrongs that are not harms *on balance,* but there are few wrongs that are not

[58] For excellent article in defense of the inviolability of persons see T. Nagel, "The Value of Inviolability", English version of "La valeur de l'inviolabilité" (1994) *Revue de Métaphysique de Morale* 149.

to some extent harms" [59] [original emphasis]. Intuitionist thinking suggests that even while an action is harmless, the 'wrong' invites moral discomfort. Feinberg believes that at a minimum, the wrong is an encroachment on liberty, which is consequentialist in nature. i.e. through disrupting my autonomy in such a way that I make poor choices. However, and importantly for the context of research, wrongs can be deontological harms, such as dignitary harm.

Recognizing and quantifying dignitary (symbolic) harm is exceptionally difficult. (Boetzkes) Gedge argues that this is because our conceptions of harm are informed by its legal understanding as the thwarting of interests, consonant with the second sense of harm presented above. But as she notes, "you may suffer an attack on dignity while material interests or significant aspirations remain untouched. Similarly, your equality and integration may be compromised while your interests are intact and you are functioning well."[60] In observational research, symbolic harm may be more pervasive than the tangible harms that can potentially follow from unsanctioned disclosures. While the latter are rare, and can be mitigated through security measures, affronts to dignity are insidious and likely to be more common and masked through attitudes. Perpetrators may not even be aware of their offense.

Dignitary harm can manifest in a variety of subtle ways. At its worst, it can be the damaging attitude of the researcher that embraces stereotypes about a group of which a person is a member. For example, in the group of affected patients with sexually transmitted disease, those found to have more than two different afflictions are judged to

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[59] Feinberg, p. 35.
[60] E. Boetzkes, "Symbolic Harm and Reproductive Practices" (2000) 3*Law and Medicine*, p 330.

be promiscuous. Perhaps this is the case for some of the cohorts in the study, and in reviewing their sexual habits from histories in the health record, it is a fair conclusion to draw. But as a new immigrant, my health record is sparse and there is no history to draw from. Moreover, my conditions were acquired through sexual assault. An overzealous researcher may be insensitive to this possibility, and in misjudging me and mischaracterizing my person he offends my dignity in the most egregious way. It matters not that I am unaware or materially unaffected by this offense, the integrity of my person has been abused.

In an illuminating discussion of genetics, disability and symbolic harm, Elisabeth Gedge challenges the argument advanced by some theorists that dignity, as a presupposition of morality, cannot itself motivate moral action (or inaction) on the part of others, and cannot be advanced or diminished in the way that interests are.[61] She convincingly responds that "while it may be true that one's moral worth cannot be damaged or repaired or even enhanced, one's moral worth *may* be acknowledged or denied, taken into account or sidelined, respected or discounted. These moral attitudes and expressions can be measured for moral appropriateness, can be judged and found wanting….".[62] Gedge is right. Researchers who spuriously draw inferences or shape their research questions around false perceptions, gender stereotypes, and socio-economic and racial prejudices, abuse the dignity of the subjects and communities whose

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[61] E. (Boetzkes) Gedge, "Genetics, Disability and Symbolic Harm" (2007). Available: http://www.inter-disciplinary.net/mso/hid/hid4/gedge%20paper.pdf . Also appearing in *Social Studies of Health, Illness and Disease : Perspectives from the Social Sciences and Humanities,* Peter L. Twohig and V. Kalitzkus, eds. (Amsterdam/New York: Rodopi, 2008).

[62] Ibid, p. 8.

information is manipulated in these ways, even if they bear no mal-intent.[63] Additionally, they do damage to the research enterprise by abusing the trust of the public in violating expectations people have concerning respect for human subjects. If these transgressions were to come to light, society as a whole would be harmed, for there would be widespread suspicion and distrust in researchers and institutions, possibly thwarting the future efforts of honorable researchers.

5.3.3 The Vulnerability of Subjects and Susceptibility of the Marginalized

The insidious nature of dignitary harm is magnified when we take account of who is likely to be wronged in this way. Recall the example in chapter one of the single mothers on social assistance that had given birth to babies with congenital heart defects; the research question asked what proportion of these mothers had a prior arrest record. Is it probable that all mothers of babies born with heart defects will be investigated for having a prior arrest record, or are poor mothers likely to be singled out? We need not answer the question with any certainty to understand that there are groups of people in society that are vulnerable to exploitation and routinely marginalized. Women, children, visible minorities, the aged, the sick, the poor and those with diminished competence are amongst them. Members of these groups are likely to be additionally stigmatized in research, particularly when dealing with sensitive information relating to disease and lifestyle habits. The vulnerability of these groups is recognized in policy governing research conduct. Respect for vulnerable persons is a foundational principle in the Tri-

[63] We might add the lack of judgment or neglect in assessing how findings might affect persons.

Council Policy Statement, and it calls explicitly for special consideration to be given to vulnerable persons in research:

> Respect for dignity entails high ethical obligations towards vulnerable persons….Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation or discrimination. Ethical obligations to vulnerable individuals in the research enterprise will often translate into special procedures to protect their interests.[64]

It may be queried why the conduct of observational research, which involves no contact with the subject and merely uses information, should be more threatening to the interests of vulnerable persons than all other persons whose information is used. Wouldn't all subjects of such research be equally vulnerable – particularly since the information is anonymised and the identities of individuals are unknown? Wouldn't anonymity equalize any pre-existing disparities between subjects? Unfortunately, no; let us examine why this is not the case.

Michael Kottow draws a distinction between 'the vulnerable' and 'the susceptible' which can usefully illuminate the difference between ordinary persons and marginalized persons as subjects of research. According to Kottow, "vulnerability is a human condition from which we all suffer."[65] Consider that all humans are fallible, mortal, and at risk of exploitation from their fellow men; precisely the kind of vulnerability that would have made life in the Hobbesian natural world 'nasty, short, and brutish'. O'Neill assesses human beings as being "*persistently* vulnerable typical of the whole species" and elaborates that in specific circumstances they can become "*deeply*, *variably*, and

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[64] TCPS , article C [i.5].
[65] M.H. Kottow, "The Vulnerable and The Susceptible" (2003) 17:5-6 *Bioethics*, p. 461.

selectively vulnerable"[66] [original emphasis]. This increased depth of vulnerability is what Kottow describes as being 'susceptible'. Being susceptible is a state where some sort of deprivation predisposes individuals to 'additional and compound forms of harm'.[67] In other words, there are features of these individuals that make them exceptionally and especially vulnerable.

Returning now to Feinberg's earlier distinction between a *harmed* condition and a *harmful condition,* we can see that any subject whose data is inappropriately used and disclosed can be harmed. Where no significant outcome follows, the subject is harmed in the sense that he was wronged by having his confidentiality breached. In at least some cases, however, the harm will be serious and palpable, and the confidentiality breach is then also harmful, e.g. when health insurance or employment benefits are denied as a result of the breach. This is the scenario that unfolds in relation to a *vulnerable* data subject. Now consider how it might be somewhat different for a *susceptible* data subject. Susceptible research subjects are exceptionally vulnerable by virtue of some pre-existing deprivation. They lack social equality, economic means, health, and other basic goods that lead O'Neill to describe them as 'destitute'. Kottow's susceptible subjects are the marginalized persons we noted earlier. When susceptible subjects suffer a breach of confidentiality, they are harmed in much the same way that any other data subject is harmed. Additionally, because of their exceptional vulnerability, the breach is also harmful – even if it did not translate into a tangible harm. It is harmful because it is one

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[66] O. O'Neill, *Towards Justice and Virtue* (Cambridge: Cambridge University Press, 1996), p, 192-193.

[67] Kottow, p. 462.

more way in which someone who is systemically oppressed is once again diminished. It is like being the innocent student in class who time after time is accused of stealing pencils because he is poor and has none of his own. If one time the well-to-do student is erroneously singled out, it is regrettable, but not offensive to the same degree. The fact that the poor boy is repeatedly singled out, not because of his character or prior evidence of stealing, but because of his circumstances, further impoverishes him by abusing his dignity. What is offensive is the presumption that someone who is poor and without pencils would be the obvious thief. In the same way that it is objectionable that single mothers on social assistance might be presumed to have prior arrest records.

To be clear, a *harmless* breach of confidentiality harms individuals to the extent that they are wronged. Furthermore, there are wrongs which are symbolic harms, such as affronts to the dignity of individuals and communities. In some cases, the individual is harmed in this non-tangible way, but on the whole it is not harmful to him, because it does not thwart or setback any further interests. However, for especially vulnerable data subjects, who we might call susceptible, harmless breaches can always be harmful, because the harm contributes to the systemic oppression they endure, thereby further setting back their interests.

In this chapter I have attempted to broaden the 'social objectives' model of confidentiality by accounting for the principle of respect for persons and showing that confidentiality can capture broader interests than the individual interest in privacy. I argued that respect for persons entails recognizing data subjects as persons and appreciating their contribution to research. Since respect is fundamentally an attitude, I

have advocated for a change in attitude in those who engage in research: acknowledging that there are persons behind the data who are vulnerable and susceptible to being harmed in a variety of ways through the use of their data in research. Additionally, recognizing that use of the data is a privilege and not an entitlement, and its use in the absence of consent, even within acceptable ethical parameters, represents a breach of confidentiality nonetheless. The breach is justified insofar as the various interests of the subject, such as dignity and privacy remain protected, while social interests are advanced. This broader view of confidentiality depends in large measure on trust, and I will now turn my attention to it in the next chapter.

--Chapter 6—

Trust in Confidentiality

Sissela Bok writes, *"Whatever* matters to human beings, trust is the atmosphere in which it thrives"[1] [original emphasis]. Confidentiality surely matters to patients and subjects, and without trust it cannot be sustained. Trust is the foundation of confidential relationships, and the relationship thrives or languishes as trust grows or diminishes. The reliance on confidentiality in research to protect privacy and the various other interests of the public depends in large measure on a culture of trust. But why should the public trust researchers and institutions? On what basis are they justified in trusting? And how is trust sustained? We must have answers to these questions if confidentiality is to be the principle capable of protecting the interests of research subjects.

Trust is the most fundamental element of confidentiality and is thus in the interest of subjects and researchers that it be sustained. In the absence of trust, researchers cannot justifiably continue to use personal information without consent. In this chapter, I consider the nature of trust and how it is promoted and undermined in the research context.

I begin with a consideration of the so called 'crisis of trust', the common belief that there is an ongoing decline of public trust in civil institutions. This claim is shown to be unwarranted.

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[1] S. Bok, *Lying* (New York: Pantheon Books, 1978), p. 31.

Next, I examine the nature of trust; an attitude that accepts vulnerability. Vulnerability is what distinguishes trust from reliance. When trust is broken, we are betrayed because the trustee has failed to look out for our vulnerability. In contrast, we are only disappointed when reliance fails. In the context of research, we rely on researchers to do good work, but we trust them to look out for our interests.

In trusting researchers and institutions we assume that they are trustworthy. Our analysis suggests that this is true for the most part. There are examples of abuse of trust by those in positions of power, but this is insufficient to merit complete withdrawl of trust. We must place trust selectively and encourage trustworthiness. Trustworthiness, however, is insufficient to foster trust on its own–although it is a good start. To build a culture of trust in the research enterprise we also need to promote openness, transparency, and action from ethical principles.

6.1 Can Trust be Trusted?

The reliance on confidentiality to protect those interests we outlined in the previous chapter depends on a 'culture of trust': that researchers are trustworthy (and so are institutions), that the public trusts, and that researchers trust that the public trusts in them. This latter aspect of trust is essential if researchers are to justifiably continue to use and disclose personal information in research without consent. For without the confidence that the public trusts in their efforts, what justification beyond the utility of the research itself would investigators have to proceed? At first glance, the dependency on trust to bolster our case is risky. Trust is fragile and fleeting; staking an entire enterprise

on its steadiness may prove unwise. O'Neill remarks that public trust in medicine, science and biotechnology appears to have steadily diminished against the backdrop of globalization and technological progress.[2] The public, it seems, are less willing to trust; they see too many risks associated with contemporary science and medicine to warrant continued trust.

Sociologists fret about western societies having become 'risk societies', yet O'Neill argues that the claims of 'risk societies' are less about the actual risks and more about the perception of risk. Those living in western liberal democracies can do no less to control risks than those living in poorer nations faced with the threats of famine and endemic disease. Claims about risk, according to O'Neill, are really about "widespread loss of confidence in the capacities of medical, scientific and technical progress to solve problems, and about a corresponding growth in reported anxiety and mistrust."[3] Paradoxically, these views have currency among people who live longer and healthier lives. Consider:

> "Scientific success and reduction of risks to life, health and the environment are manifest not only in research, but also in the application of research to medical practice and environmental protection. Life expectancy has risen and is still rising in the richer world, and also in many (but not all) parts of the poorer world. Medical care has been improving, and many serious health problems are now ones that individuals can address for themselves, for example by stopping smoking or drug use, or by losing weight or exercising more."[4]

Yet despite the advances made in improving the general quality of people's lives, the public appears to be suspicious and distrustful of science and scientists, and O'Neill

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[2] O. O'Neill, *Authonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002), p. 8.

[3] Ibid.

[4] Ibid, p. 11.

queries, "why should trust be declining at a time when reasons for trusting have apparently grown?"[5]

If public trust in medicine is indeed in decline then we cannot reliably construct a model of interpersonal ethics that depends on trust. We must have the trust of the people to move forward with research that takes place in the absence of consent. Fortunately, things are not as bleak as they seem when it comes to trust. While an atmosphere of distrust appears to loom large, there is substantial evidence to the contrary. The public continues to place trust "not only in doctors, but also in the scientists who develop new medicines, in the industries that produce them and in the regulators who ensure safety standards."[6] O'Neill explains that the dissonance between reported perceptions and action reflects the ways in which claims about trust do not mirror how people actually place trust. Subtly implied in O'Neill's analysis of why people 'talk the talk, but don't walk the walk', is what can crudely be described as sheep mentality. Driven by a few mishaps that abuse public trust, the people are momentarily suspicious and then cling to this suspicion because a few others do. Distrusting public institutions, public servants and professionals, is what is rationally expected in the face of abuse. But once the hoopla subsides, most people continue to place trust though refusing to admit it. For who would be foolish enough to be duped again? Instead, they go along with the masses in endorsing suspicion, while continuing to place trust in the institutions they profess to distrust.

If this is how it really is, then we can confidently proceed in developing a system that relies on trust. At bottom, if the public genuinely trusts scientists, then we are not off

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[5] Ibid.
[6] Ibid, p. 9 .

the mark in thinking that they will trust in their research. However, there is another way to interpret why people claim to distrust health professionals while continuing to depend on their services. Sporadic abuses of trust cause irreparable damage to the reputation of institutions and professionals, but we can suppose that people are required to continue placing trust in them out of necessity. In other words, vulnerability compels people to 'trust' in health professionals they are suspicious of. So while people may not actually trust doctors, it matters not because they need to obtain healthcare. In other words, people appear to be trusting, but it is only because they have no other choice –if they did, they would cease to go to doctors, consume medicine, support research, etc… If this is the actual state of affairs, then it bodes very badly for research, since there is no compelling reason to 'reluctantly cooperate' with scientists. In the absence of a direct benefit to be gained, what motivation is there to overlook genuine distrust?

This highly skeptic interpretation presents a pessimistic view of human nature consistent with egoism, which I think few would readily embrace. Most of us want to believe that human beings are charitable and forgiving, that we can look beyond past transgressions, and that we are fundamentally altruistic. Human beings are relational beings, and it is natural to want to form and repair relationships rather than rebuke them. Consider what Trudy Govier has to say about what makes trust possible:

> "[T]rust is possible because we are believing, feeling creatures who have a sense of ourselves and our own needs. We are, in addition, creatures who respond naturally to other creatures, primarily to other human beings, on whom we depend and who depend on us. We have a sense that other people are beings with whom we will be involved in close relationships, that they are caretakes and potentially

> our sympathetic companions, and that they are free agents who could choose to harm us but usually will not."[7]

I am thus inclined to agree with O'Neill's interpretation that people fundamentally trust, even when there are reasons not to. She also notes the practical implications of complete suspension of trust and correctly recognizes that, "just as total skepticism would produce total paralysis of belief, and is untenable in practice, so total inability to place trust would produce total paralysis of action, and is untenable in practice. In practice we have to take a view and place our trust in some others for some purposes. Where people perceive others as untrustworthy they may place their trust capriciously and anxiously,...But they do not refuse to trust."[8]

Assuming then, that the public is capable of trusting researchers (and institutions) even in the face of suspicion, we can proceed with examining the three questions asked at the start:

1) Why should the public trust researchers and institutions?
2) On what basis are they justified in trusting?
3) How can trust be sustained in the confidential relationship?

Before we can answer these questions, we must consider the nature of trust.

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[7] T. Govier, *Social Trust and Human Communities* (Montreal & Kingston: McGill-Queen's University Press, 1997). p.7.
[8] O'Neill (2002), p. 12.

6.2 The Nature of Trust

"Trust is both important and dangerous"[9] – so says philosopher Carolyn McLeod. Her assessment is particularly gripping in the context of observational research. Without trust, confidentiality collapses and the research cannot ethically proceed in the absence of consent; at the same time, misplaced trust in the confidential relationship puts subjects at risk of exploitation and abuse.

6.2.1. Trust is an Attitude

McLeod claims trust is an attitude that we take towards others.[10] Trudy Govier also sees it as an attitude, "based on beliefs and feelings and implying expectations and dispositions".[11] For McLeod, the expectation is that the other will be trustworthy, which is a property and thus distinct from trust. Prominent philosopher of trust Annette Baier describes trust as a feeling, a Humean 'impression of reflexion' that responds to "how we take our situation to be". [12] Later she clarifies that it is one of those 'mental phenomena' that is especially difficult to classify as 'cognitive', 'affective', or 'conative', because trust is all three.

> "It has its special 'feel' most easily acknowledged when it is missed, say, when one moves from a friendly 'safe' neighbourhood to a tense insecure one. It has its (usually implicit) belief component, belief in the trusted's goodwill and competence, which then grounds the willingness to be or remain within the

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[9] C. McLeod, "Trust", *Stanford Encyclopedia of Philosophy.* Available: http://plato.stanford.edu/entries/trust.

[10] Ibid.

[11] Govier, p. 4.

[12] A. Baier, *Moral Prejudices : Essays on Ethics* (Cambridge, Massachusetts : Harvard University Press, 1994), p.131.

> trusted's power in a way the distrustful are not, and to give the trusted discretionary powers in matters of concern to us."[13]

6.2.2. Vulnerability

Trust, as we noted earlier, implies vulnerability on the part of the person who trusts. Theorists seem to agree:

> Baier: "When we trust we accept vulnerability to others."[14]
>
> Govier: "When we trust, we take risks and are vulnerable. There are not guarantees, and it would be an indication of lack of trust to look for them."[15]
>
> McLeod: "One important condition for trust is that the truster accepts some level of risk or vulnerability. Minimally, what this person risks, or is vulnerable to, is the failure by the trustee to do what s/he depends on that person to do."[16]

McLeod's claim that a refusal to be vulnerable undermines trust or prevents its manifestation and Baier's idea that the truster 'accepts' her vulnerability, suggests that individuals are conscious of their vulnerability—and of their trusting, but this need not be the case, trust can be subconscious.[17] Trust can be voluntary and formal, as when one intentionally hands over the care of something to someone, but as Baier remarks, "trusting is rarely begun by making up one's mind to trust, and often it has no definite initiation of any sort but grows up slowly and imperceptibly...Trust can come with no beginnings, and with various degrees of self-consciousness, voluntariness, and

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[13] Ibid, 132.
[14] Ibid.
[15] Govier, p. 4
[16] MacLeod. Available at http://plato.stanford.edu/entries/trust.
[17] Baier, p. 99.

expressness."[18] Moreover, trust is so familiar to us that we scarcely take notice of it,[19] and O'Neill claims that we notice only when it fails. In trusting, we can suppose that we are sometimes aware of our vulnerabilities and at other times we are not. Neither philosopher comments on what the relationship might be between the extent of vulnerability and the corresponding depth and breadth of trust required. I am inclined to think that the more vulnerable you are, the more trust needs to be placed. Trust exists in various degrees, so we can indeed trust more or less.

But the idea that increased vulnerability demands more trust seems to be at odds with the experience of trust in relationships. We trust in those with whom we have well-defined and established relationships, such as lovers, friends and colleagues, and we might say we trust them a lot, but we are not as vulnerable in these relationships as we are in relation to strangers. Baier remarks that, "we trust those we encounter in lonely library stacks to be searching for books, not victims. We sometimes let ourselves fall asleep on trains or planes, trusting neighbouring strangers not to take advantage of our defenselessness."[20] Govier refers to the trust we place in those we barely know as 'thin trust',[21] perhaps because it thinly disguises suspicion and doubt. But it seems to me that depositing trust in a stranger or in someone who has not yet shown his trustworthiness requires a greater leap of faith, and in this sense the trust is anything but thin. We might call it blind trust, since there is no evidence in past experience on which to base it.

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[18] Ibid, p. 105.
[19] Ibid, p.98.
[20] Ibid. 98.
[21] Govier, p. 6.

6.2.2 Expectations: goodwill, moral integrity or 'standing for something'?

Trust varies between persons and contexts, in both duration and intensity, yet there appears to be an 'essence or logical core of trust' which persists across the varieties of forms of trust. Govier identifies the commonalities as: "confident expectations of benign action (competent and well motivated); an overall sense that the other person or party is basically decent and will act decently towards us; acceptance of risk and vulnerability; and dispositions to interpret the actions of the other in a positive way."[22]

Govier's points on the essence of trust line up with Baier's account, although Baier states unequivocally that goodwill on the part of the trustee is essential –"when I trust another, I depend on her goodwill toward me."[23] This last point is controversial and has inspired considerable debate among philosophers of trust. The criticism goes something like this: for others to make good on our trust they need only fulfill our expectations, to be competent in the ways we had imagined they would be. There is nothing in the concept of trust itself that compels the trustee to adopt any sort of attitude towards us, let alone goodwill. O'Neill sees it at most in select personal relationships.

> "When we place trust in others, we do not usually trust or even expect them to have our interests entirely at heart, let alone to place our interests ahead of all other concerns…Our trust in individuals and in institutions, in officials and in professionals, does not (fortunately!) rest on the thought that they have good will towards us. The thought that placing trust requires good will has a context (at most) in personal relationships –and perhaps not in all of those."[24]

[22] Ibid, p.7.
[23] Baier, p.99.
[24] O'Neill, p.14

McLeod has similarly challenged the idea that the trustee is motivated to act out of goodwill. She gives a persuasive argument that it is moral integrity, rather than good will, that we expect from those we trust.[25] However, moral integrity is not enough, since agents differ on what it is they have 'the most moral reason to do', thus in the relevant domain, the truster and the trustee must be able to 'stand for something' sufficiently similar. According to McLeod, "our attitude toward people we trust, therefore, targets both their moral integrity and what they stand for…[S]ometimes, it also concerns their perception of their relationship with us."[26] The last two points are intriguing. McLeod argues that we *care*[27] about what the trusted other stands for and not just about whether they act on it. In other words, if I trust that a researcher will not sell my personal information to a drug company, I trust her because I have a sense about what she stands for in this regard (presumably that she is against turning a profit on the backs of research subjects). Moreover, this matters to me, and not just that she will not the sell my data. In McLeod's words, "to trust others, usually we need some sense of what they stand for so that we can know whether they are likely to act in the way that we would expect them to if we were to trust them. The way that we expect them to act depends on what we perceive to be morally acceptable ways to act."[28]

This interpretation of trust is admirable in that it captures the moral dimension of trust that distinguishes it from mere reliance,[29] that is, the sense in that in trusting

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[25] C. McLeod, "Our Attitude Towards the Motivation of Those We Trust" (2000) 38 *The Southern Journal of Philosophy* 465.

[26] Ibid, p.466.

[27] Ibid, p.471.

[28] Ibid.

[29] The distinction between trust and reliance is discussed below.

someone, we expect them 'to do the right thing'. 'Doing the right thing' is intuitively more than just complying with an action or omission, it suggests motivation. One problem with this approach, however, is imagining what strangers or those in whom we deposit 'thin' trust, stand for. Would we not have to have some knowledge about a person or some fairly well developed relationship to have a sense of what they stand for? According to McLeod, it is sufficient to assume that others have at least some common values with us in a shared society. "If we could not assume that –either because we knew that we were wildly eccentric and had totally unique values, or because we were recent immigrants to this country and were uncertain about what values people held in common here –then we would have a lot of difficulty trusting people."[30] Here, I think we have a problem for a pluralist society. Unless we define 'common values' it will be challenging, to say the least, to gauge what others stand for –particularly others whom we know nothing about.

6.3 Trusting the Trustworthy?

6.3.1 Trusting Professionals

The challenge of not knowing what others stand for is not insurmountable in our context. I think it is possible to have some understanding of what professionals stand for in their profession. That is, certain *roles* 'stand for something', so that we can assess with some confidence what values attach to those roles independently of what the role-bearer would stand for as an individual. For example, a fireman or a policeman in those roles

[30] McLeod (2000), p.472.

stand for 'saving lives', and we trust with reasonable confidence that they would risk their own to save ours. In the same way, a healthcare professional stands for 'improving health' or 'patient welfare', and some roles in healthcare, e.g. nursing, have well defined values that most members of society can readily identify as standing for the profession. Of course, it is easier to identify what some professions stand for. Most people would be able to easily articulate what doctors, firemen, policemen, paramedics, teachers, lawyers, judges and professors stand for, but would find it more challenging to pinpoint what actors and politicians stand for. Researchers are probably somewhere in between on the continuum of what is easily identifiable and what is obscure. Some people might say that researchers stand for 'knowledge', 'innovation' or 'discovery'; the pessimistic lot might say they stand for 'publications', 'self-promotion' and 'recognition'; and still others might hail that they stand for 'the betterment of humanity'. The point is, that it is not always easy to assess what someone stands for and hence whether trust is warranted, but some social roles exemplify shared common values that can usefully guide us.

Baier starts from the position that we should trust, and only when we have reason not to trust should we withdraw it; trust in social roles seems to proceed in this way. If our trust is betrayed, say by a policeman, we are cautious of trusting another policeman—maybe we will not trust one again—but there is a good chance that we will. Intuitively, policemen are just the sorts of people that we trust, and if in our experience one has betrayed that trust, we may just chalk it up to 'one bad seed'. The ease with which we can rationalize the merit of trusting professionals that have in the past broken our trust illustrates the kind of affective pull certain professions and social roles have on us. This

is the way in which trust is dangerous; intuitionist thinking is unreliable and we should trust on the basis of experience. But if McLeod is right that "our trust tends to grow or diminish as knowledge of what others stand for increases"[31], then we can reconcile why we continue to place trust in social roles that have disappointed us in the past. The bad policeman who betrayed our trust stood for corruption and lawlessness, so if we encounter him again (or someone like him), we will not trust them. However, policemen *in general* stand for the rule of law, social order and justice, so we can continue to trust most police officers that we meet.

The other point that McLeod makes regarding the motivation of those we trust concerns the nature of the relationship. She argues that sometimes to be optimistic that others will honour our trust depends on whether they interpret the relationship in the way we do, but this is relevant only to certain kinds of trust relations.[32] This caveat accounts for unwelcome trust –trust that has not been invited or acknowledged. We can imagine that if the other person views the relationship differently, she may not be moved to act in accordance with our expectations. Some theorists take the rejection of trust to be a signal from the trusted person that they do not wish to be counted on, i.e. to do something for us.[33] However, McLeod objects to this interpretation claiming that it ignores the fact that we do not always count on those we trust to do something for us. And if we do count on them, we might not expect them to acknowledge our trust or even be moved by it. If moral integrity and standing for something is what moves people to act, then the thought

[31] McLeod (2000), p.473
[32] Ibid, p. 475
[33] Ibid.

that I might be counting on you is redundant –you are moved by your moral commitments.[34]

This is an interesting perspective and I think that McLeod is correct that the interpretation of the relationship determines whether trust will be deposited and accepted. In the context of fiduciary relationships, where there are clear expectations about mutual obligations, and trust is either implicitly or explicitly acknowledged, this is less of a concern. The parties to the relationships in such cases may even have different understandings about the relation and corresponding expectations, but there is likely to be some basic agreement regarding trust, and the problem of unwelcome trust will not be a problem at all. For our analysis, however, interpreting the relationship and what trust is required to sustain it is a problem. Researchers and subjects do not have a direct relationship. How does each party perceive the 'relationship'? What trust are subjects willing to submit and researchers willing to honour? In considering these questions we need to give some additional thought to trust in professions and roles, since ultimately this is the kind of trust we are dealing with.

6.3.2. Abuse of power, abuse of trust

So far we have only considered one half of the story regarding trust in professionals and social roles. Our discussion above intimated that people tend to trust persons in specific social roles because we attach certain values to those roles, or perceive

[34] Ibid, p. 476.

them as McLeod does, as 'standing for something.' However, sometimes those very same roles can be the source of angst, suspicion and distrust. Consider:

> "Many people are uneasy about dependence on experts and professionals. Sensing professional power, intimidated by specialized knowledge, people feel vulnerable. Sexual abuse of women patients by doctors; malpractice suits; deceitfulness and fraud on the part of lawyers; corruption or vested interest on the part of scientists and professors; child molestation by teachers and clergy –are all ongoing stories in the press, making many people uncomfortable with the status and power of professionals....Many ask whether professionals can be trusted to fulfill the crucial roles society has assigned them."[35]

Abuses by those in trusted positions of power have led to what is often called the 'crisis of trust'[36], the unfortunate situation where the public widely mistrusts experts in medicine, science and biotechnology. The specialized knowledge and status that professionals enjoy creates opportunities for abuse. The lay public must defer to the experts to do what needs to be done because we lack the knowledge and expertise to do it ourselves. Thus we depend on professionals to exercise these powers, believing them to be reliable and trustworthy. To be reliable, the professional must exercise her knowledge and skills in the appropriate fashion; to be trustworthy, she must demonstrate moral qualities.[37] A reliable dentist will use her skills and knowledge to perform a needed tooth extraction, and if she is trustworthy, she will not propose to do a costly root canal for pecuniary gain.

Govier lists three essential qualities of being a professional: "...possession of *powerful knowledge*; considerable *autonomy* in regulation; and a high level of

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[35] Govier, p. 77.
[36] O'Neill (2002).
[37] Govier, p. 83.

responsibility to serve the interests of clients and the general public"[38] [original emphasis]. The responsibility is fiduciary and is related to trust. The circumstances of scientists who carry out their research without ever having contact with their subjects may obscure the fiduciary aspect of their responsibility towards them. However, the observational researcher's obligation to maintain confidentiality and protect the interests of indeterminate subjects is no different from the obligation of researchers towards particular subjects in clinical trials, for example. Researchers in general have privileges and obligations associated with their professional roles that do not change with context.

Researchers may presume that the public 'trusts' them, but not know what they trust in them for. Do subjects trust in the quality of their research, i.e. their methods, findings, results, etc..? Do they trust that as subjects they have not been misrepresented and harmed in some way? Perhaps they believe researchers to be reliable, but not trustworthy. Quoting Benjamin Barber, Govier tells us that "scientists's commitment to public welfare is suspect because they are too prone to assume that what *can* be done *must* be done."[39] So while the public may have confidence that researchers use their knowledge and skills suitably in the advancement of their craft, they may doubt whether scientists ever question the moral implications of their work. A good example of where we see this happening is in stem cell and cloning research.

6.3.3 Trust versus Reliance

Trust has a moral dimension related to the attitude of the trustee which is absent from reliance. Reliance has to do with expectations around the application of skill and

[38] Ibid, p. 79.
[39] Ibid, p.97.

knowledge; it is functional, almost mechanical in quality, as when we say we rely on our car for transportation. Simply relying on researchers to do good work is insufficient if you are a subject of that work. As a subject you have a stake in the enterprise, you are vulnerable and at risk, so you must trust that the researcher will not only do good work, but will protect your interests in the process. The distinction between reliance and trust is an important one here, and one that researchers must recognize. A researcher who fails to protect the subject's interests in the course of otherwise laudable research acts reliably but betrays trust. This can happen because the researcher may be oblivious to the trust that has been placed in him.

Trust can be confounded with reliance because trust can be mixed with other forms of psychological reliance that depends on the attitudes and actions of others. The crucial difference is that we are merely *disappointed* when someone we relied on fails us, but *betrayed* when trust is broken. "The trusting can be betrayed, or at least let down, and not just disappointed."[40] The moral difference seems to point to the extent of vulnerability. If we are vulnerable we trust, but if we are confident we mostly rely on the skills of others, though most cases of reliance can also include trust.[41] For example, we rely on mail carriers to deliver the mail in a timely fashion, but we trust that they will not open and read it before they deliver it. The expectation with regards to reliance is the confidence in the discharging of some function –that is why we are only disappointed when it fails. Trust, on the other hand, is an admission of vulnerability and we expect that the trustee will look out for us in this respect.

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[40] Baier, p. 99.
[41] Govier, p. 119.

On Baier's account, trust "is letting other persons (natural or artificial, such as firms, nations, etc..) take care of something the truster cares about, where such 'caring for' involves some exercise in discretionary powers."[42] The 'caring for' cashes out as good will for Baier. However, that others might 'take care' of some interest we have is perfectly compatible with other motivations besides good will. They might do so, as McLeod maintains, because they are morally committed. In fiduciary relationships, such as the attorney-client relation, the motivation may be entirely driven by a legal norm, though the relationship presupposes a great deal of trust.

Thus far our analysis has revealed that trust is an attitude, and that it can be conscious or unconscious. Trust implies vulnerability on the part of the truster, and the expectation that the trustee will honour the trust. In honouring the trust, we expect that the trustee will do more than fulfill the requirement that we are relying on, for that would be mere reliance and failure to comply would result in disappointment, but not betrayal; only broken trust ends in betrayal. Trust has a moral dimension, and we expect that trustees fulfill the requirement because it is the right thing to do. Thus in accepting trust, trustees acknowledge that we are vulnerable and they must be motivated to action out of moral commitment. In the end, the attitude of those we trust matters because we are vulnerable and need a reason to trust.

Trust comes in a variety of forms and we can trust more or less, implicitly or explicitly. There is an epistemology to trust in that knowledge and past experience guides our willingness to trust and our assessment of who is trustworthy, although trust can be

[42] Baier, p. 105.

blind and guided by nothing more than intuition. Some trust is based on confidence in social roles that we associate with particular values that we embrace, for example trusting in doctors and firemen because we value health and safety. However the asymmetry in power between truster and trustee can lead to abuse of trust, which then causes distrust (both warranted and unwarranted).

6.4. Trustworthiness

Trust is possible because people are trustworthy. We remarked earlier that trustworthiness is a property, a quality of a person, like being generous or thoughtful.[43] Trust is well placed if the recipient is deserving of trust. That is, the trustee has proven herself reliable and of good moral character; in such cases it is easy to place trust. How are we to assess trustworthiness in others? We can start by consulting past experience. If on previous occasions the trustee has demonstrated being worthy of trust, by honouring the trust that either I or others have placed in her, we can infer that she is trustworthy. I can also judge someone to be trustworthy based on knowledge gathered through the experience of others, as when my friend assures me her auto mechanic is trustworthy.

We also assess others to be trustworthy based on specific social roles. For example, parents are deemed unquestionably trustworthy by their children. If mom and dad say they are taking me camping, I trust that we are going on a family vacation and returning home afterwards. I do not worry that they will abandon me in the woods. This

[43] McLeod (2006). Available: http://plato.stanford.edu/entries/trust.

is because parents *as parents* are trustworthy.[44] I may not, however, trust mom to remove my appendix when it bursts in the middle of the night. Unless mom is also a surgeon, removing my appendix is not part of her parental responsibilities, and it is not something that I expect her to do.

6.4.1 Are Researchers Trustworthy?

Judging trustworthiness in researchers is difficult in the specific context of observational research. Subjects will have had no contact with them and thus no opportunity to draw from experience. We are left to assess the trustworthiness of the profession (in general), or of the institution at which the research takes place. Considering the history of medical research and some of the deplorable abuses that have occurred, such as the Nazi experiments, the Tuskegee Syphilis Trial, and some of the documented cases of ethically suspect research in the developing word, [45] there is clear cause for distrust. Suspicion towards researchers may be aroused or compounded by unexpected tragedy and unfavourable study outcomes, such as what happened in the Jesse Gelsinger case and more recently in the Jolee Mohr case.[46] However, nothing as grave as death needs to occur to fan the flames of suspicion; periodic reports of mishaps involving

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[44] This is why we are outraged and find it particularly shocking when parents abuse the trust of their own children. It is counter to the idea of *being a parent* to betray that trust. Media reports of parents who abandon their children or propose to sell them on the internet to predators usually look for some psychological pathology to explain this behaviour because the idea that a parent would just do that is counterintuitive and hard to grasp.

[45] For example, the placebo-controlled trials of vertical HIV transmission in Thailand during the early 1990's. See Phanuphak, P. "Ethical Issues in Studies in Thailand of Vertical Transmission of HIV" (1998) 338:12 *New England Journal of Medicine* 834.

[46] S.G. Stolberg, "Institute Restricted After Gene Therapy Death", *New York Times,* May 25, 2000; and R. Weiss, "Death Points to Risk in Research", *Washington Post,* August 6, 2007; and

unlocked filing cabinets, stolen laptops and patient files discarded in dumpsters are all reasons to distrust researchers.[47] O'Neill sums up the reasons why researchers might not be trustworthy:

> "[T]here are cases of outright fraud that go beyond disingenuous communication and evasion: scientists, biotech companies and journalists all sometimes misreport and exaggerate the significance of new discoveries; scientific misconduct and fraud sometimes arises from competition for grants, results and glory; peddlers of untried and untested remedies sometimes prey on desperate people. Sporadic deception can be found almost anywhere…"[48]

However, abuses in health research are still the exception and not the norm. The abuses documented above have involved contact with subjects and are pernicious. The vast majority of contemporary research is nowhere as treacherous, and much of it is quite commendable. We have to resist temptation to cast wholesale suspicion over the entire research enterprise. Consider that the abuses likely to occur in our context of interest will be more a product of ignorance than malevolence, giving hope to the idea that proper education and training can go a long way to correcting some of the potential problems.

Harmful breaches of confidentiality do take place, but most are of the harmless sort that need to be confronted with ethical sensitizing and not with blanket distrust. O'Neill asks if trust should be withdrawn when there is evidence of untrustworthiness or inadequate evidence of trustworthiness. She claims that wholesale distrust is intrinsically incoherent: it is neither feasible nor practical. "It is not feasible because our lives depend in a myriad ways on medicine, science and biotechnology. We cannot avoid using them

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J. Burman, "St.Joe's patient files found in dumpster behind coffee shop", *Hamilton Spectator,* August 17, 2008.

[48] O'Neill, p. 120.

except by withdrawing from the modern world."[49] From a practical perspective, refusing to trust the products and knowledge of modern-day research would compel us to place trust elsewhere[50], perhaps uncritically, and leading to disastrous results.[51] If blanket skepticism towards research is not feasible, the best we can do is place trust selectively and urge that trustworthiness be vigorously promoted in our institutions.

6.4.2 Are Institutions Trustworthy?

The trustworthiness of institutions is another way to gauge whether one should trust its researchers. To some extent, the moral character of the researchers cannot be divorced from the institution; the integrity of the former depends on the reputation of the latter. Researchers of repute and moral integrity will not thrive at an institution filled with corruption and deceit, with a reputation for 'cutting corners' and 'bucking the system'. They will know that career aspirations elsewhere could be limited thereafter. Empirical research shows that people highly trust researchers based at public institutions such as hospitals and universities to keep their personal information confidential. In contrast, they reported high distrust of the private sector, and to a lesser extent, the government.[52] We can only speculate on the reasons for this disparity in trust levels, but I am inclined to believe that people trust university and hospital researchers because they are seen as pursuing ends consonant with the public interest, e.g. discovering cures, improving health, etc…; whereas the public sector and government are viewed as

[49] Ibid, p. 121

[50] In other products and knowledge; O'Neill offers the example of alternative or exotic medicines, which offer no more than anecdotal evidence for safety and efficacy.

[51] Ibid, p. 121.

[52] Willison et al (2007), "Consent and Health Research", p.708.

pursuing financial gain and economic efficiency, respectively. In other words, researchers in the public system stand for something that the public can relate to. Consider this: Who do we find more trustworthy – a researcher at the Hospital for Sick Children or one at GlaxoSmithKline?

Trustworthy researchers are more likely to be found at trustworthy institutions. A 'culture of trust' implies both. How is a culture of trust fostered in research? How is it sustained? Clearly the trustworthiness of the relevant actors has to be a central consideration. Onora O'Neill offers what I think are plausible ideas for promoting trustworthiness, and hence trust, in the research enterprise. She argues for greater transparency, or as she calls it, 'trustworthiness through openness' that promotes sharing information with the public. The idea is that institutions and practices that are not mired in secrecy are less cause for suspicion, and more likely to be supported and trusted. Implicit in this argument is a call for greater public engagement. She also suggests that trustworthiness can be promoted by incorporating ethical principles into the life of an institution. In her view, ethical conduct is part and parcel of good science and good medicine, so that meeting with ethical obligations is consistent with, and not opposed to, satisfying other non moral obligations. However, in her view these measures only go as far as promoting trustworthiness, which is insufficient for securing trust. The latter is elusive and will need time to be built up and repaired where damaged, but we can all do better by acting from principles that all can adopt and be more responsive towards meeting our ethical obligations.

O'Neill argues for the seamless integration of ethical principles into the policies and practices of the institution, noting that ethical requirements are *also* satisfied in any course of action that satisfies the other requirements (technical, scientific, clinical, etc…). In other words, fulfilling ethical obligations should not be onerous or considered an impediment to fulfilling the other obligations the agent has. Ethical principles when applied with the aid of practical judgment help the agent navigate through the multiple constraints he faces.

She considers the many steps that can be taken to improve the trustworthiness of practices in medicine:

> "Fundamental ethical obligations, the rejection of coercion and deception among them, set demanding standards. Their embodiment in legislation, regulation, public policies, institutional practice and professional standards is the first and central way of improving trustworthiness. Good legislation, good regulation, good policies, good practices and consistent professionalism are a beginning; they need reinforcing with means of ensuring compliance, and demonstrating that compliance is reliably achieved."[53]

In her view, these measures are easily stated, but difficult to implement; the difficulties are both philosophical and practical in nature. We have the problem of moving from abstract ethical principles to determinate structures and acts.[54] The question is asked: "How can indeterminate principles ever guide action, given that every act is particular and determinate?"[55] The worry is that ethical principles inevitably underdetermine policies and action in given contexts. O'Neill dismisses this challenge against

[53] O'Neill, p. 123.
[54] Ibid.
[55] Ibid.

principlism, claiming that critics assail 'any truck with principles', confusing them with life algorithms.[56] Her response is that since principles do underdetermine action, they need to be complemented with the exercise of practical judgement (which is not a matter of arbitrary choice).

> "…[J]udgement is eased rather than thwarted by the commonplace fact that multiple requirements have to be satisfied. We do not generally dither about which of many possible non-deceptive acts to do, because much of the indeterminacy is resolved by the fact that we are always also pursuing a range of aims, and simultaneously meeting numerous other constraints."[57]

O'Neill is confident that practical judgment can aid us in the application of principles — since there is 'nothing mysterious about the exercise of practical judgment'—but she may be assuming too much about the rational nature of the actors and not enough about the specificity of context. She concedes that it is difficult to apply practical judgment in these contexts, but "*ethical principles are always needed in the middle of lives and activities in which action and practices, policies and institutions are constrained in multiple ways*"[58] [original emphasis].

O'Neill goes on to say that there is "no difficulty in principle in incorporating and living up to ethical principles in the practice of medicine, science and biotechnology…"[59], the practical challenge is compliance. Both institutions and individuals can fail to be compliant, and failure ultimately damages trustworthiness.[60] To prevent this from

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[56] Ibid.
[57] Ibid, p. 124.
[58] Ibid.
[59] Ibid, p. 125.
[60] Ibid, p. 126.

happening (and to remedy it once it has), trustworthiness is pursued through a relentless 'audit agenda'.[61] Consider:

> "[N]ew and more detailed measures to improve trustworthiness are constantly proposed and frequently introduced at every level. They aim to secure more trustworthy performance by enforcing more detailed compliance with more demanding prescribed procedures…"[62]

> "[A] prominent feature of this widespread movement to improve accountability has been an increasing reliance on more formal procedures, including contracts, letters of agreement and financial memoranda that impose highly complex conditions…Formalisation has advantages that are constantly mentioned by its advocates: mutual clarity of expectations, clear performance targets, defined benchmarks of achievement, enhanced accountability."[63]

Yet systems of accountability through audit have only served to undermine trust. While greater compliance may be achieved on some levels, it is not achieved on others because standards are obscured and priorities distorted through increased bureaucracy. "The new forms of audit make institutions more complex and obscure both to those who staff them and to those whom they supposedly serve."[64] According to O'Neill, the old ways of pursuing compliance and accountability can be described as *qualitative*, *internal* and *local*. They examined the *primary activities* of institutions in *real time*, allowing for self correction.[65] The new systems are *quantitative*, *external* and conducted *at arm's length* usually *retrospectively,* "they manifest *low trust* of those being called to account"[66] [original emphasis]. The results of increased monitoring and discipline are widely disseminated and held up for public scrutiny, but rather than instill trust, the statistics are

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[61] Ibid, p.129.
[62] Ibid.
[63] Ibid, p. 130
[64] Ibid, p. 133.
[65] Ibid, p. 132.
[66] Ibid.

uncritically received and become a source of more distrust[67]: "half the schools and hospitals audited will be demonstrably below average (scandalous!); distinguished teaching hospitals will have the highest death rates (they treat the worst cases)."[68] The audit agenda is hopelessly cynical and some forms of audit are ultimately damaging to professional standards and ethical responsibilities. As O'Neill notes, "those who find their clocks watched begin to watch their clocks; those who find their professional competence measured and judged by trivializing standards find that institutional loyalty and professional honour wane."[69]

6.4.3 Openness

O'Neill considers building trustworthiness through 'openness'. The idea is to allow for transparency about the activities of institutions and professionals "by ensuring that information is available to the public, including interest groups and campaigning organizations, who may then use that information to hold institutions, experts and officials to account."[70] She certainly sees openness as an improved alternative to audit, but has concerns nonetheless about its effectiveness. Like the audit agenda, regimes of openness still require 'prodigious documentation', it is not clear that the public knows what to do with the information, and she is sceptical of public consultation methods, e.g. town halls and citizen's juries.[71] These are all legitimate concerns.

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[67] Charles Raab might disagree; recall his suggestion to publicize privacy violations as a deterrent for future violators. He might argue that such a mechanism of account might inspire trust in the public.

[68] O'Neill, p. 133-134.

[69] Ibid, p. 134.

[70] Ibid, p. 135.

[71] Ibid, p. 134, 169-174.

However, I think O'Neill presents a very narrow conception of 'openness'. What she describes as openness is limited to disseminating information about institutional activities, which sounds more like reporting. Openness has to include genuine participation on the part of the public, and involves more than just being told what is done behind closed doors. We have to question whether this characterization of openness is accurate.

She appears unconvinced that the openness agenda which is governed by the Nolan Principles in the UK can do much to promote trust.[72] According to O'Neill, the seven ethical principles established to guide the standards of conduct in public life – selflessness, integrity, objectivity, accountability, openness, honesty and leadership—can improve trustworthiness, but not trust. Yet I wonder if this is a fair criticism. Integrity, openness and honesty arguably are principles that can inspire trust. Would we hesitate to trust an open and honest person who demonstrates integrity?

Furthermore, her criticism of public engagement is not incisive; these methods may not be perfect, but can be improved. She understands public consultation as merely canvassing of public opinion, wary that there is insufficient thoughtful deliberation or understanding about what is being asked. But this can be remedied through improved education efforts. There is no reason to think the public would not welcome or value being better schooled in matters pertaining to health research. We might consider having greater participatory action on the part of the public in setting the research agenda. As it is, we assume that research priorities and approaches established by institutions are

[72] Ibid, p. 135.

shared by the public at large. This can be misguided. For example, the epidemic proportion of diabetes prevalence within the Aboriginal population has prompted extensive efforts to address the problem. Much of the research is aimed at studying genetic predisposition and identifying behavioural and lifestyle modification approaches that can be integrated into the Aboriginal way of life. However, many in the Aboriginal community do not view diabetes as an organic disorder, a physical ailment that warrants medical intervention; they view it as a 'spiritual' disease, caused by the drifting away from the traditional habits of the people.[73] Weakness in spirit, they claim, has allowed Native peoples to be corrupted by the White man's food, which in turn causes the White man's disease. It is interesting that scarcely a few decades ago, diabetes was virtually nonexistent in this population, and it begs the question: why look for the 'diabetes gene' in this group? Do researchers think that genetic intervention is an appropriate strategy to address a 'spiritual disease'? Integrating lifestyle and behaviour modification strategies into the aboriginal way of life seems sensible, but taking a 'genetic' approach is questionable. This is an example of where the research agenda set by mainstream investigators does not coincide with the needs of the population under study, a population which clearly has had limited input into the research question.

A culture of openness can foster an atmosphere of trustworthiness, which in turn contributes to building trust. And public engagement *can* be useful towards this goal by promoting the education and involvement of the public. O'Neill sees its limits, whereas I

[73] Giles, B.G., Findlay, S.C., Haas, G., LaFrance, B., Laughing, W., and Pembleton, S. "Integrating conventional science and *aboriginal* perspectives on *diabetes* using fuzzy cognitive maps" (2007) 64:3 *Social Science and Medicine* 562.

see the potential. An analogy might be helpful: We can imagine openness as a sport, let's say a soccer game. On O'Neill's account, the public are spectators, sitting in the bleachers watching the game, fully apprised of the rules, the players, the penalties, and the goals. On my account, the public is part of the team: when necessary they can contest the rules, negotiate with the coach, and argue with the referee.

A culture of openness, however, may not be enough to secure a culture of trust. O'Neill claims that trustworthiness is neither necessary nor sufficient to guarantee trust: Cassandra's problem is our own.[74] But this may be too skeptical. To restore trust when it has been broken, it seems sensible to begin by developing trustworthiness. O'Neill proposes principled action based on ethical principles that all can adopt: the rejection of coercion and deception. From O'Neill's perspective, principled action is unfailing since the agent is normatively directed. Where virtues can fail (e.g. a lapse in judgment), ethical principles are enduring. An agent who acts from ethical principles is thus a trustworthy agent.[75] This will be the agent who we have already advocated for: the one who respects persons by seeing research subjects as ends in themselves. This is one more principle for action that everyone can adopt.

6.5 Sustaining Trust

We have some tools then, for promoting and supporting trustworthiness and trust. How shall we sustain it? The sustainability of trust will depend in large measure on those who are trusted. They will need to consistently honour the trust of the public by fulfilling

[74] Ibid, p. 141.
[75] Note how this idea resonates with McLeod's trustee being motivated by moral integrity.

their ethical obligations as researchers. This entails acting in accordance with ethical principles, such as respect for persons; being attentive to the ways in which information use and disclosure can harm persons and communities, and taking the necessary steps to prevent such harm; and finally, being sensitive to the idea that the use of data is a privilege and not an entitlement.

The public for its turn should know that their trust is not deposited in vain; this is where transparency and openness about research protocol can be informative. This is not to suggest that the conduct of research will be monitored and reported in the press –that would be audit. I am suggesting something more mundane in terms of transparency, such as basic explanations about how information is collected, used and disclosed in specific studies, and posted on institutional websites. I have often wondered about what research goes on at McMaster. It is only when a 'breakthrough' happens that we learn something, and only because it is newsworthy. I was astonished to learn that Hamilton Health Sciences (HHS) maintained over 8000 different patient databases. What are they for? What information is in there? Who uses them?

Baier has this to say about sustaining trust:

> "[T]he appropriateness of trust, of sustaining trust, and of supporting institutions that call for trust is judged case by individual case, not just when trust is given or withheld, but retrospectively, when all accounts, or enough accounts, are in. If to trust is to be willing to delay the accounting, then, when trust is successfully sustained, some accounts are bound to be outstanding."[76]

[76] Baier, p. 181

That 'some accounts are bound to be outstanding' speaks to the idea that trust cannot be sustained through the rigor of audit, and that trust implicitly accepts that there will be mishaps.

Despite the so called 'crisis of trust', the public continues to trust the very institutions they profess to distrust. It is clear from our discussion that you cannot have an ethos of distrust or society would collapse. Govier recounts the story of the Ik tribe that succumbed to such misfortune.[77] The apparent growth in distrust is fuelled in part by reports of scandals in the media. The other part is the knowledge and power asymmetry between scientists and the public that can promote scepticism, particularly when the public is excluded, uninformed, and the object –not the subject—of research. The inability to meaningfully participate in the research enterprise surely breeds suspicion and doubt, then when things go wrong –as they inevitably do –suspicions are confirmed, leading to distrust. Notwithstanding historic and periodic abuses of trust, the public is still willing to trust.

Well founded trust is essential to sustaining a culture of trust. Trustworthiness should be fostered by encouraging greater openness and transparency in the research enterprise, while trust promoted by urging researchers to act from ethical principles. In

[77] Govier, p.72-76. "They lived in an alienated and isolated condition where each person was solely out for his own good. There was virtually no co-operation, nurturance, or care for the young, the old, or the sickly. There was apparently little or no trust between members of the group. In their despair and deprivation, the Ik were neither hunters nor farmers. The people lived in loose groups exhibiting almost no social cohesion, and they were unfriendly, uncharitable, inhospitable, and generally 'as mean as any people can be'."

the absence of trust, the alternative is to turn to contractual forms of control and audit. In the end, these are not really substitutes for trust, but presuppose trust on some level.[78]

In answer to our question: why should the public trust researchers and institutions? The public should trust them because they are mostly trustworthy. The evidence for rampant abuse of trust in research is lacking for an indictment of researchers.[79] While any relationship can develop distrust, the key is to see these moments and address them as such. On what basis then, is the public justified in trusting? The complex answer is the demonstration of trustworthiness in the past, the lack of malevolence on the part of investigators, and sufficient similarity in standing for something, viz. shared interests.[80] The simple answer is that an ethos of distrust is untenable.

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[78] O'Neill (2002).

[79] I have yet to see substantial and convincing evidence in the literature of mass violations of confidentiality in research. Perhaps it simply is not studied or documented. Empirical enquiry in this regard is needed.

[80] Researchers and subjects can together stand for better and more equitable health, and research that fairly reflects a diverse and pluralist society. They can stand for protecting shared interests, viz. privacy, dignity, and the common good. Citizens should have the opportunity to be charitable in research, to want to give gifts, to identify with similar others, and not worry about being harmed in doing so. These are all things we can stand for.

-- Conclusion--

> *…if men were to regulate their conduct in this particular, by the view of a peculiar interest, either public or private, they would involve themselves in endless confusion, and would render all government, in a great measure, ineffectual. The private interest of every one is different; and though the public interest in itself be always one and the same, yet it becomes the source of as great dissentions, by reason of the different opinions of particular persons concerning it*[1].
>
> -- David Hume, *A Treatise of Human Nature*

In the fall of 2002, my father received a thick package in the mail from the Department of Surgery at McMaster University. In the giant manila envelope was a lengthy questionnaire (approximately 60 pages), several requisition forms for laboratory tests and an invitation letter to participate in a research study. The letter went something like this:

> Dear Mr. (Name),
>
> As a patient affected with Dupuytren's Contracture you are eligible to participate in a study ……Patient's with this condition are invited to come to the Department of Surgery…….

Almost immediately I received the phone call from my dad. He was distressed about learning of his 'new' condition. Why hadn't his family doctor told him? Clearly it must be very serious; after all, the Department of Surgery at the University wanted to see him.

When my dad read through the letter, he only focussed on the medical term for his 'condition', strange and exotic as it was. He did not notice that it was an invitation to participate in research. It was not until I read the documents myself and assured him that

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[1] D. Hume, *A Treatise of Human Nature* (1739). ebooks@Adelaide, 2006. Available: http://ebooks.adelaide.edu.au/h/hume/david/h92t/index.html

it was only a study that he ceased to be anxious. He was amused to discover that the 'tendon problem' on his left hand was referred to as Dupuytren's Contracture – no one had ever mentioned that to him before. The letter claimed that he had been referred to the study by a Dr. P, but Dr. P was not my father's family physician and he could not remember who she was. Later we discovered that she was a specialist that he had visited once for a cortisone shot, the year before.

I was annoyed with Dr. P for sharing my dad's information with the researchers without his consent, particularly since she wasn't his family physician. But my dad did not seem to mind. He was relieved to know he was not suffering from a terminal illness. In fact, his response was quite surprising to me. He said, "I thought patient files belonged to the Ministry of Health. Doesn't that mean that anyone who works in the system sees your information?"

It is a truism that what is in the public domain is not private. My dad's perception of the 'system' explains why he had such a low expectation of privacy. I am not sure how many people would share his view, but many citizens are concerned about the privacy of their health information and how it is accessed, used and disclosed. The incident was enough to prompt the present inquiry.

In this thesis, I have tried to show that confidentiality is broader than the concern for individual privacy, and thus a concept worthy of greater attention in the research context. In observational health research, individual privacy is not the only interest at stake. The privacy of entire communities can be affected, and so can the dignity of

persons. Confidentiality can capture these interests in a broad moral framework informed by a mix of deontological and consequentialist concerns.

Re-framing the privacy issue in health research as one of confidentiality will depend on whether the issue ceases to be viewed in the liberal individualist tradition as strictly about privacy endorsing autonomy. So long as individualism and autonomy continue to be privileged values, confidentiality will continue to be the residual concept. Confidentiality presupposes vulnerability and depends on trust. Asking individuals to relinquish control of their information in favour of trusting someone to protect it, may be asking too much. It is giving up autonomy in exchange for vulnerability. Why would anyone want to do that?

The reality of observational research, however, is that subjects have already relinquished autonomy and become vulnerable –except that nobody asked. Epidemiological studies, disease surveillance, quality improvement, and a host of other research initiatives proceed in the absence of consent. To this extent, perhaps my father's perception was not off the mark. Researchers have access to an abundance of data maintained in the healthcare system – private interests in the service of the public good. Once at this stage, it is too late to speak of privacy; the information has already been accessed and seen. It is prudent to speak of confidentiality. Confidentiality is a fiduciary obligation, where the trustee recognizes the vulnerability of the truster and must look out for their best interests. In doing so, the researcher must acknowledge the data subject as a person, a person with interests that can be harmed if due care is not exercised in the use and further disclosure of the data. Taking such care is not onerous. It requires moral

sensitivity and commitment to acting from ethical principles that all can adopt. At the very least, it requires acknowledging that use of the information is a privilege and not an entitlement.

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