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# CONSPIRACY THEORY: BIG BROTHER ENTERS THE BRAVE NEW WORLD OF HEALTH CARE REFORM

*Wendy Wuchek\**

## INTRODUCTION

In 1996, Congress passed the Kennedy-Kassebaum Health Insurance Portability and Accountability Act<sup>1</sup> that was meant to allow people to retain their medical insurance when changing jobs.<sup>2</sup> A little known provision of the Act requires Donna Shalala, the Secretary of the Department of Health and Human Services, to create a unique health identifier (ID) for every American.<sup>3</sup> This proposed national health ID would establish a national health database consisting of the medical records of every American.<sup>4</sup>

The purpose of the ID is to facilitate medical treatment from the cradle to the grave.<sup>5</sup> A national patient identifier would allow health care providers to access a person's entire medical history simply by

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<sup>1</sup>See Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 23 U.S.C and 42 U.S.C.).

<sup>2</sup>See *Health ID Numbers* (NPR July 21, 1998) (reported by Cheryl Corley) [hereinafter Corley].

<sup>3</sup>See *Hearing on National Identifiers before the House Subcomm. on National Economic Growth, Natural Resources and Regulatory Affairs*, September 17, 1998, available in 1998 WL 18088525 (opening statement of Chairman David McIntosh) [hereinafter McIntosh], See also 42 U.S.C. § 1320d-2(b) (Supp. III 1996) ("The Secretary shall adopt standards providing for a standard unique health identifier for each individual, employer, health plan and health care provider for use in the health care system").

<sup>4</sup>See Corley, *supra* note 2.

<sup>5</sup>See *Stop This Dangerous Idea; Health Identification Card Would Further Erode Privacy*, THE GRAND RAPIDS PRESS, Aug. 11, 1998, at A8 [hereinafter *Stop This*].

pressing a few numbers on a computer keypad.<sup>6</sup> The arduous process of assembling one's medical records piecemeal would be a thing of the past.<sup>7</sup> Furthermore, researchers and scientists could utilize this pool of data for unlimited clinical research purposes.<sup>8</sup> For example, Food and Drug Administration (FDA) drug testing would be facilitated by a nation-wide database since patients following the trial protocol would not necessarily have to go to a specific clinic to be followed.<sup>9</sup>

The government maintains that a national health ID would also reduce paperwork and make the health care industry more efficient.<sup>10</sup> Indeed, it is estimated that the health care industry could save one percent annually once the ID system is instituted.<sup>11</sup>

This article will address the legal and ethical implications of a national health identifier as it applies to patients. Specifically, four different topics will be discussed. First, this article will describe the various proposed forms such an ID may take. Second, the benefits of a national health ID will be addressed. Third, this article discusses the legal and ethical problems posed by an ID. Finally, this paper analyzes proposed privacy legislation to prevent abuses of a national patient identifier.

## PROPOSED FORMS

Over sixty years ago the federal government instituted the nation's first national identification system under the auspices of the Social Security Administration.<sup>12</sup> Without a Social Security number (SSN), it is difficult to obtain a job, open a bank account, procure a driver's license, or retrieve a birth certificate.<sup>13</sup> Since its inception, there have been

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<sup>6</sup>*See id.*

<sup>7</sup>*See id.*

<sup>8</sup>*See id.*

<sup>9</sup>*See* Amy M. Jurevic, *When Technology and Health Care Collide: Issues with Electronic Medical Records and Electronic Mail*, 66 UMKC L. REV. 809, 811 (1998).

<sup>10</sup>Dana Hawkins, *Medical ID Plan Stirs Fears of Big Brother Keeping Health History Secret Would Be Harder*, U.S. NEWS & WORLD REPORT, Aug. 3, 1998, at 62.

<sup>11</sup>*See id.*

<sup>12</sup>*See* Corley, *supra* note 2.

<sup>13</sup>*See* *Hearing on National Identifiers before the House Subcomm. on National Economic Growth, Natural Resources and Regulatory Affairs*, September 17, 1998, available in 1998 WL 658010 (statement of Hon. Ron Paul) [hereinafter Paul].

almost forty congressionally authorized uses of the SSN as an identifier for non-Social Security programs.<sup>14</sup>

One of the proposals for implementing the national health identifier is to use the Social Security number.<sup>15</sup> A national health ID using Social Security numbers would be the least expensive means of complying with the provisions set forth in the Health Insurance Portability and Accountability Act.<sup>16</sup> Robert Gellman, a Washington, D.C. based privacy consultant serving on the Department of Health and Human Services committee charged with making recommendations for the national health ID, estimated the cost of adopting the Social Security number for this purpose to be in excess of \$10 billion.<sup>17</sup>

Other proposals for the ID include issuance of an alphanumeric number, distinguishable from the Social Security number.<sup>18</sup> This alphanumeric number could be combined with a photo to prevent fraud.<sup>19</sup> Another idea is a card with a "smart chip."<sup>20</sup> This card would

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<sup>14</sup>See *id.* See also Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 460-61 (1995) (stating, "Since the SSN originated in 1936, it has been used extensively for a large variety of purposes that are not related to social security. Although the Privacy Act of 1974 makes it unlawful for a government agency to deny a right, benefit or privilege because of a refusal to disclose a SSN, several federal departments do use these numbers, including the Internal Revenue Service, Department of Defense, Parent Locator Service, Food Stamp Program, and Selective Service system. The SSN is also widely used in other government agencies and in the private sector, including debt collectors, department stores, utilities, check validation services, supermarkets, cable television, credit card issuers, banks, major oil companies, mailing list companies, credit bureaus, insurance companies, the Medical Information Bureau, motor vehicle departments, law enforcement agencies, employers, schools, and universities. The extensive use of the SSN in the public and private sectors leads to concern that it has become a de facto national identifier"). See also Lisa L. Dahm, *Using DNA Profile as the Unique Patient Identifier in the Community Health Information Network: Legal Implications*, 15 J. MARSHALL J. COMPUTER & INFO. L. 227, 243 (1997) (explaining, "Initially, the social security number was intended as 'a means to track earnings to determine the amount of Social Security taxes to credit to each worker's account.' Over time, however, use of the social security number has become widespread, and the public is becoming increasingly concerned about its potential abuse.").

<sup>15</sup>See *infra* pp. 11-12 (discussing the arguments for and against implementation of the Social Security number as the national health identifier).

<sup>16</sup>See Hawkins, *supra* note 10. But see Gostin, *supra* note 14 at 459 (estimating that, "The process of verifying the identities of all holders and reissuing Social Security cards would cost between \$1.5 to \$2.5 billion").

<sup>17</sup>See Hawkins, *supra* note 10.

<sup>18</sup>See *id.*

<sup>19</sup>See *id.*

<sup>20</sup>See *id.* See also Gostin, *supra* note 14 at 461-62 (describing "Four types of plastic wallet-sized cards could be used for the collection, retention, use, and disclosure of portable

include a microchip from which health care professionals could download a person's medical records.<sup>21</sup> Still another proposal calls for a biometric identifier.<sup>22</sup> The biometric identifier would be either a fingerprint or a retina scan,<sup>23</sup> since each person's fingerprint and retina scan is unique.<sup>24</sup> It has also been suggested that an individual's unique deoxyribonucleic acid (DNA) fingerprint be used.<sup>25</sup> Implementation of any of these ideas would cost the government, health care providers, payers and patients billions of dollars.<sup>26</sup>

### Benefits Of National Health Identifier

Do the benefits of implementing a national patient identifier justify the financial costs? Insurers and medical researchers think so.<sup>27</sup> According to the Mayo Clinic's Christopher Shute, assembling lab results, x-rays and other important medical information in one place will facilitate better treatment and ensure continuity of care for patients.<sup>28</sup>

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files of personal information: embossed, magnetic strip, integrated circuit, and optical storage cards. Integrated circuit cards that have the capacity not only to store information, but also to manipulate that information, are often called 'smart cards.' Smart cards provide a medium for the storage of the equivalent of 800 printed pages").

<sup>21</sup>See Hawkins, *supra* note 10. See also *infra* pp. 13-14 (discussing the pros and cons of using a smart card as the national health identifier).

<sup>22</sup>See Hawkins, *supra* note 10.

<sup>23</sup>See *id.*

<sup>24</sup>See *id.*

<sup>25</sup>See Dahm, *supra* note 14 at 244-46 (suggesting that "[t]he success of any identification number system depend on the uniqueness of the numbers used; a number must be able to 'minimize or eliminate the risk of misidentification.' Yet in the healthcare industry, it is also critical that an identifier not unnecessarily impede the prompt and efficient delivery of healthcare. Further, the identifier must function 'anywhere in the country and in any provider's facilities and settings...[and]...be able to link events that have occurred at multiple providers.' Once an individual's DNA fingerprint is reduced to a bar code, the numerical representation of that code easily meets the critical success factors of a unique identification number system. Not only is each individual's DNA unique to him or her, but an individual's DNA is not subject to theft, loss, or fraudulent use by others who might have access to the number. Laboratory specimens are routinely collected from people who receive services within the healthcare delivery system. Even if a person were to 'forget' his bar code number, another DNA profile could be generated specifically for that encounter with the healthcare delivery system. A subsequent DNA profile would cause little or no interruption in the individual's treatment, and could actually yield an additional means of identity verification").

<sup>26</sup>See Hawkins, *supra* note 10.

<sup>27</sup>See Corley, *supra* note 2.

<sup>28</sup>See *id.* See also Gostin, *supra* note 14, at 459 (stating that a unique identifier, "would be used for a variety of health, administrative, financial, statistical, and research purposes. It would provide access to care and to reimbursement for services rendered. The identifier would

Medical records are currently stored in paper files.<sup>27</sup> In the United States, the thirty-four million annual hospital admissions and 1.2 billion physician visits is estimated to generate ten billion pages of medical records.<sup>30</sup> This “paper mountain” of records creates difficulty for patients and health care providers alike.<sup>31</sup> Medical records are often fragmented, poorly documented, inaccurate, incomplete or inaccessible when needed for patient care.<sup>32</sup> The proposed health identifier would eliminate the need for paper medical records and pave the way for electronic medical records.<sup>33</sup> The retrieval of electronic records would facilitate patient care and research by establishing longitudinal and geographic links among a patient’s health care records.<sup>34</sup>

Treating a patient who is unable to give an accurate medical history will be easier with access to complete medical records through the ID.<sup>35</sup> Furthermore, having an unlimited medical database will simplify research and promote analysis of diseases and treatments.<sup>36</sup> In addition, the elimination of hard copy medical records will allow patients to avoid the arduous task of assembling their entire medical record before switching health care providers.<sup>37</sup> In the long run, implementation of an ID system will save the health care industry money that would have been spent on unnecessary treatment.<sup>38</sup>

### Legal and Ethical Issues

#### the National Health Identifier System Poses

Despite the benefits, the proposed medical ID raises serious legal and ethical dilemmas.<sup>39</sup> These issues include confidentiality and privacy interests in medical records, confidentiality concerns of utilizing SSNs,

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also point to the correct patient records, and establish longitudinal and geographic links among a patient’s health care records in order to improve patient care, analyze patterns of health services, identify fraudulent activities, and provide a more detailed examination and evaluation of the health care system”).

<sup>29</sup>See Gostin, *supra* note 14, at 457.

<sup>30</sup>See *id.*

<sup>31</sup>See *id.*

<sup>32</sup>See *id.*

<sup>33</sup>See Corley, *supra* note 2.

<sup>34</sup>See Gostin, *supra* note 14, at 459.

<sup>35</sup>See Corley, *supra* note 2.

<sup>36</sup>See Corley, *supra* note 2.

<sup>37</sup>See Jurevic, *supra* note 9.

<sup>38</sup>See *id.*

<sup>39</sup>Since these issues are convoluted, they will be discussed together.

privacy concerns of utilizing "smart cards," and issues related to informed consent.

### *Confidentiality and the Privacy Interest in Medical Records*

One of the greatest concerns with the proposed national health identifier is the breach of patient confidentiality.<sup>40</sup> "Confidentiality refers to an individual's right to prevent redisclosure of certain sensitive information that was disclosed originally in the confines of a confidential relationship." Traditionally, confidentiality protected medical information.<sup>41</sup> Indeed, the duty of medical confidentiality is an ancient one.<sup>42</sup> Exemplified by the Hippocratic oath which states, "And whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secret."<sup>43</sup>

The principle of confidentiality protects the autonomy of the patient and allows patients to trust their doctors with sensitive personal information.<sup>44</sup> In the absence of confidentiality, physicians fear that their patients will withhold vital medical information which could hinder treatment.<sup>45</sup>

The principle of privacy<sup>46</sup> is rooted in the implicit constitutional right of privacy.<sup>47</sup> The "zone of privacy" created by the United States

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<sup>40</sup>See *Stop This*, *supra* note 5; McIntosh, *supra* note 3.

<sup>41</sup>See Albert R. Jonsen et al., *CLINICAL ETHICS* 166 (4th ed. 1998), See also Joan Gibson, *Thinking About the "Ethics" in Bioethics*, in *BIOETHICS: HEALTH CARE LAW AND ETHICS* 1,4 (Barry R. Furrow, 3d ed. 1997) (defining confidentiality as, "The principle that when information is divulged by one person to another with the implicit promise that it will not be revealed to any other person that implicit promise should be respected").

<sup>42</sup>See Jonsen, *supra* note 41.

<sup>43</sup>See *id.* See also Robert M. Gellman, *Prescribing Privacy: The Uncertain Role of the Physician in the Protection of Patient Privacy*, 62 N.C. L. REV. 255, 267 (1984) (describing Thomas Percival's 1803 code of medical ethics which stated, "Secrecy and delicacy, when required by peculiar circumstances, should be strictly observed. And the familiar and confidential intercourse, to which the faculty are admitted in their professional visits, should be used with discretion and with the most scrupulous regard to fidelity and honor").

<sup>44</sup>See Jonsen, *supra* note 41.

<sup>45</sup>See *id.*

<sup>46</sup>See Mark A. Rothstein, *Genetic Privacy and Confidentiality: Why They Are So Hard To Protect*, 26 J.L. MED. & ETHICS 198, 198 (1998) (defining confidentiality as, "the right of an individual to prevent redisclosure of certain sensitive information that was disclosed originally in the confines of a confidential relationship").

Supreme Court protects an individual's right to make decisions concerning marriage, contraception, procreation and raising children free from governmental intrusion.<sup>48</sup> In particular, Justice Douglas, in his concurring opinion in *Roe v. Wade*<sup>49</sup> stated that the, "right of privacy has no more conspicuous place than in the physician-patient relationship."<sup>50</sup>

Nevertheless, the right to privacy and confidentiality regarding one's medical records has never been held absolute. Thus, a compelling state interest can justify access to medical records without informed consent of the patient. For instance, public health concerns can outweigh the privacy interest in avoiding disclosure of an individual's human immunodeficiency virus (HIV) status.<sup>51</sup>

Ultimately, confidentiality may not offer the protection patients believe it does.<sup>52</sup> First, there exist two generally acknowledged exceptions to the confidentiality rule—"concern for the safety of specific persons and concern for public welfare."<sup>53</sup> Second, confidentiality is often treated carelessly by the health care industry.<sup>54</sup> For instance, "providers may speak about patients in public places"<sup>55</sup> and "records are not well secured and are accessible to many persons, including some who are not health professionals."<sup>56</sup>

Additionally, confidentiality of medical records is not afforded adequate protection by the law.<sup>57</sup> Indeed, state law regarding confidentiality of medical records varies and to date there is no

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<sup>47</sup>*See id.* (defining privacy as, "the limited access to a person, the right of an individual to be left alone, and the right to keep certain information from disclosure to other individuals."); Terri Finkbine Arnold, *Let Technology Counteract Technology: Protecting the Medical Record in the Computer Age*, 15 HASTINGS COMM. & ENT. L.J. 455, 472 (1993).

<sup>48</sup>*See Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (holding that parents are free to make decisions regarding child rearing); *Loving v. Virginia*, 388 U.S. 1 (1967) (holding that the right of privacy extends to marriage); *Griswold v. Connecticut*, 381 U.S. 479 (1965) (holding that the right of privacy extends to contraceptive use); *Roe v. Wade*, 410 U.S. 113 (1973) (holding that the right of privacy includes a woman's right to terminate her pregnancy).

<sup>49</sup>*See Roe*, 410 U.S. at 119 (Douglas, J., concurring).

<sup>50</sup>*See id.*

<sup>51</sup>*See Arnold*, *supra* note 47, at 474.

<sup>52</sup>*See Jonsen*, *supra* note 41.

<sup>53</sup>*See id.*

<sup>54</sup>*See id.*

<sup>55</sup>*See id.*

<sup>56</sup>*See id.*

<sup>57</sup>*See Jonsen*, *supra* note 41 at 167.

comprehensive federal law defining confidentiality.<sup>58</sup> Thus, proponents of a national health identifier argue patient privacy will not be impinged upon anymore than it is now once a health ID is implemented.<sup>59</sup> Nevertheless, the National Committee on Vital and Health Statistics has suggested that implementation of a national health identifier be delayed until patient confidentiality legislation can be enacted.<sup>60</sup>

### *Analysis of the Social Security Number as a Unique Health Identifier*

Implementation of the national health ID using the SSN raises additional confidentiality concerns. First and foremost, opponents of the idea argue Social Security numbers are already subject to corruption and abuse.<sup>61</sup> "Average citizens already are forced to deal with the widespread use and abuse of their Social Security number by creditors, insurance companies, employers, retailers and so forth."<sup>62</sup> One privacy advocate noted:

Not only does the SSN make it easier for large institutions to compare their databases, it allows curious individuals (including private detectives, computer hackers or other strangers you might not want snooping in your private life) to 'hop' from database to database and draw out a profile of your buying habits and personal lifestyle.<sup>63</sup>

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<sup>58</sup>See *id.* But see Allison Wielobob, *The Medical Records Confidentiality Act: Understanding Its Intent*, 24 HUM. RTS. 15, 20 (1997) (discussing the proposed Medical Records Confidentiality Act which, "is intended to establish uniform federal guidelines for use and disclosure of health information, delineating the circumstances in which disclosure is permissible and to which audiences disclosure is appropriate. The legislation sets severe civil and criminal penalties for breaches of medical records privacy and is designed 'to set a uniform federal standard for handling medical records'").

<sup>59</sup>See Gostin, *supra* note 14, at 460.

<sup>60</sup>See *National Provider ID Standard Still Not Released*, INFO. TECH. REPORT, Feb. 1, 1998, available in 1998 WL 11694881.

<sup>61</sup>See *Stop This*, *supra* note 5; Paul, *supra* note 13.

<sup>62</sup>See *Stop This*, *supra* note 5.

<sup>63</sup>See Gostin, *supra* note 14, at 460 (citing *Use of Social Security Number as a National Identifier*, Hearings Before the Subcomm. on Social Security of the House Comm. on Ways & Means, 102d Cong., 1st Sess. 101, 106 (1991) (testimony of Evan Hendricks, publisher and editor, Privacy Times)).

Advocates of adopting the Social Security number counter-argue that any identifier adopted for health care purposes would eventually be widely available to interested parties.<sup>64</sup> Since so many authorized users would have access to a health identifier, such as hospitals, doctors, insurers, researchers and system administrators, it would be difficult to ensure that the number would remain private.<sup>65</sup> Furthermore, once a health identifier was implemented, the government could decide that the ID would be an effective means of accomplishing other tasks, such as identifying illegal immigrants.<sup>66</sup>

Opponents of the Social Security number also argue that it is not a unique identifier.<sup>67</sup> Often more than one person has been assigned the same nine-digit Social Security number.<sup>68</sup> The overlapping numbers would have to be verified and new numbers issued to correct this problem.<sup>69</sup> Verification of every SSN would increase the cost of implementing a national health identifier exponentially.<sup>70</sup>

### *Analysis of "Smart Cards" as Unique Health Identifiers*

One alternative to using the SSN as the national health identifier is to employ electronic card technology or "smart cards."<sup>71</sup> Proponents of smart cards suggest that smart cards would be the most beneficial health identifiers due to their storage capabilities.<sup>72</sup> Smart cards would ultimately reduce paperwork, limit the costs of processing insurance claims, improve diagnostic accuracy, and facilitate accessibility of medical records.<sup>73</sup> It has been suggested that:

The memory of a smart card could be divided into several zones, each with different levels of access and security. Public zones could contain the cardholder's identification while usage zones could contain emergency information, vaccination history, and medical history. Confidential and

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<sup>64</sup>See *id.*

<sup>65</sup>See *id.*

<sup>66</sup>See *id.*

<sup>67</sup>See *id.* at 459.

<sup>68</sup>See Gostin, *supra* note 14, at 459.

<sup>69</sup>See *id.*

<sup>70</sup>See *id.*

<sup>71</sup>See *id.*

<sup>72</sup>See *id.* at 462.

<sup>73</sup>See Gostin, *supra* note 14, at 462.

secret zones could contain more sensitive information such as sexual or needle-sharing behaviors and psychiatric diagnoses. Several technologies are available to restrict access to sensitive data, including personal identification, user verification, and cryptography.<sup>74</sup>

Yet the smart card also raises privacy concerns.<sup>75</sup> Since a smart card would store and retrieve data maintained in a larger database, it would not protect the privacy of medical information anymore than current paper medical records.<sup>76</sup> Indeed, the smart card would create an additional privacy risk because of the computerization of medical information.<sup>77</sup> If medical information is stored in electronic databases accessible through the smart card, then conceivably computer hackers, could obtain unauthorized access to private medical information.<sup>78</sup> Shelley Abbott, of the AIDS Foundation of Chicago, stated "There are very real threats to the availability of insurance coverage as well as to things like employment, housing, child custody, education and other areas that are unrelated to health care by unauthorized and inappropriate use of confidential medical information."<sup>79</sup>

In addition, a smart card identifier would be vulnerable to theft or fraud.<sup>80</sup> Robert Gellman, a privacy and information policy consultant, stated, "unless you start tattooing identifiers on people, you're gonna

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<sup>74</sup>See *id.* at 462-63.

<sup>75</sup>See *id.* at 463.

<sup>76</sup>See Jurevic, *supra* note 9.

<sup>77</sup>See *id.*

<sup>78</sup>See *id.* (stating, "Critics of electronic medical records state that electronic medical records make unauthorized access to medical records easier than access to paper medical records. Computerization enables large amounts of data to be stored in a small physical space; therefore, an individual may access a large amount of data once the individual has access to the system").

<sup>79</sup>See Corley, *supra* note 2. See also Gostin, *supra* note 14, at 487 (discussing that, "There is a market for the 'sale of personal information from both public and private sources, encouraged by financial incentives for staff to supplement their income through unauthorized disclosures of personal information.' Unauthorized access to personal information can be motivated by many factors. These include profiting from the sale of data to information brokers or marketing firms; uncovering sensitive information about famous individuals such as a history of mental illness, HIV infection, or a sexually transmitted disease; possessing information that may be helpful in litigation such as malpractice actions; and using the information to make employment or insurance decisions").

<sup>80</sup>See Corley, *supra* note 2.

have people who walk into hospitals or other places and hand over somebody else's ID card."<sup>81</sup>

### *Informed Consent*

Another fear is that patients will have no control over access to their own medical records with the implementation of a national health identifier.<sup>82</sup> As patients will have given consent to access in a general way, they cannot realistically govern the manner in which data is utilized.<sup>83</sup> The purpose of informed consent is to honor the participant's autonomy while relieving the provider of liability.<sup>84</sup> It also frees the provider from the burden of beneficence, to do no harm to his patient.<sup>85</sup> As such, an informed consent relieves the provider from trying to weigh the benefits of confidentiality with the risks associated with disclosure. Finally, an informed consent gives the provider the opportunity to establish a rapport with the patient and build a level of trust.<sup>86</sup> Thus, the advocates of the proposed national health identifier could only benefit from an informed consent signed by patients before release of medical information.

Finally, the most frightening aspect of the proposed national health identifier is the power it gives the government over the private lives of citizens. The proposal brings to mind the Big Brother government described by George Orwell in his science fiction masterpiece, *1984*.<sup>87</sup> The difference here is that this is not fiction, but reality. People fear that a government regulated health identifier will essentially turn the United States into a dystopic nightmare. Indeed, Representative Ron Paul (R-TX) testifying before the House Subcommittee on National Economic Growth stated:

The creation of these identifiers represent perhaps the greatest threat to liberty facing Americans today. When one closely examines the details of these schemes it becomes clear that the proponents of Big Government wish to forbid Americans

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<sup>81</sup>See *id.*

<sup>82</sup>See Gostin, *supra* note 16, at 487.

<sup>83</sup>See *id.*

<sup>84</sup>See Jonsen, *supra* note 32.

<sup>85</sup>See *id.*

<sup>86</sup>See *id.*

<sup>87</sup>See GEORGE ORWELL, *1984* (1949).

from going to work, getting on board a plane, seeing a doctor or conducting any other major life activity without their federally-approved identifier. Such a system is incompatible with American liberty. If history teaches us anything, it is that when government gains the power to monitor the actions of the people, it eventually uses that power to impose totalitarian controls on the populace. America could very well come to resemble Nazi Germany or Soviet Russia, where state officials could arbitrarily punish innocent citizens for failure to produce the correct "papers."<sup>88</sup>

While such fears may seem ridiculous it is the fear of government intrusion into the realm of privacy that fuels the opposition to the proposed health identifier. As such, several legislators have suggested means of preventing governmental trespass.

### *Analysis Of Proposed Privacy Legislation*

The legal and ethical implications of the national health identifier, mandated by the Kennedy-Kassebaum Health Insurance Portability and Accountability Act, have led several representatives and senators to propose bills that would prevent implementation of the national health identifier as provided for in the Act.

For example, Representative Ron Paul (R-TX) has proposed a bill that would revise the Act to eliminate the provision mandating the health identifier.<sup>89</sup> In support of his bill, Representative Paul stated, "The federal government has no authority to endanger the privacy of personal medical information by forcing all citizens to adopt a uniform health identifier for use in a national database."<sup>90</sup>

Meanwhile, Representative Steve Chabot (R-OH) with several other representatives has proposed an alternative plan.<sup>91</sup> Representative Chabot suggests that the Kennedy-Kassebaum Act be rewritten so that implementation of the national health identifier program would require

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<sup>88</sup>See Paul, *supra* note 13.

<sup>89</sup>See *Politics & Policy Privacy: Chicago Tribune Looks at Controversy*, AMERICAN POLITICAL NETWORK – AMERICAN HEALTH LINE, Aug. 31, 1998, at 6.

<sup>90</sup>See *id.*

<sup>91</sup>See Editorial, *No Snooping: Another Wrong Number; National Health ID an Unhealthy Intrusion*, THE CINCINNATI ENQUIRER, Aug. 12, 1998, at A10.

a vote of Congress.<sup>92</sup> In the alternative, Representative Chabot has suggested that an amendment could be made to the Act that would eliminate appropriations for implementing the ID.<sup>93</sup>

Probably the best proposal for modifying the national health ID legislation has been made by Senator Patrick Leahy (D-VT).<sup>94</sup> Senator Leahy's proposal addresses the informed consent issue.<sup>95</sup> He suggests a privacy act be adopted that would require a court order for access to a patient's medical records without authorization from the patient.<sup>96</sup> Nevertheless, Senator Leahy's privacy act would allow unauthorized access of medical records for research purposes.<sup>97</sup>

While none of these proposals address all of the legal and ethical dilemmas posed by the national health identifier one thing is certain: without patient privacy legislation, initiatives to establish a national database of medical records will be fruitless.

## CONCLUSION

An analysis of the proposed health identifier, mandated by the Kennedy-Kassebaum Act illustrates the legal and ethical dilemmas facing health care reform in the United States. While the benefits of a patient identifier – including increased accessibility to medical records, improved quality of patient care, and lower costs of health care – are apparent, the means of implementing such a program remain unsure.

The initial obstacle that must be overcome is determining the form that the ID will take. Whether the social security number or another identifier is used, the cost of instituting the identifier program may outweigh the projected one percent savings the health care industry expects from using the identifier.

The fate of the patient identifier is hindered by the confidentiality issue. In the absence of substantive privacy legislation, the plan is unlikely to move forward. In addition, until federal patient privacy legislation is established, most citizens will be wary of a government

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<sup>92</sup>See *id.*

<sup>93</sup>See *id.*

<sup>94</sup>See Editorial, *Spying on Patients, Plan for Federal Health Care I.D. Poses an Invasion of Public Privacy*, COLO. SPRINGS GAZETTE, July 23, 1998, at 6.

<sup>95</sup>See *id.*

<sup>96</sup>See *id.*

<sup>97</sup>See *id.*

regulated patient identifier. The threat of a Big Brother government controlling the private medical records of every citizen is too important to be ignored by the Legislature.

The fact that the health identifier is to be created by the Secretary of Health and Human Services, Donna Shalala, is no comfort to those that fear government invasion of their medical records. As Representative Steve Chabot suggests implementation of a patient identifier should rest in the hands of the democratically elected Congress.<sup>98</sup>

Ultimately, the fate of the patient health identifier is uncertain at best. While the benefits of the program are great such an endeavor will not succeed until the general public is comfortable with evolving technology. Until patients are assured that their medical records are confidential and private, a national database of medical records should remain an idea out of the pages of science fiction.

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<sup>98</sup>See Editorial, *No Snooping: Another Wrong Number; National Health ID an Unhealthy Intrusion*, THE CINCINNATI ENQUIRER, Aug. 12, 1998, at A10.