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## A Healthy Amount of Privacy: Quantifying Privacy Concerns in Medicine

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# A HEALTHY AMOUNT OF PRIVACY: QUANTIFYING PRIVACY CONCERNS IN MEDICINE

IGNACIO N. COFONE\*

## ABSTRACT

With recent developments in e-health, concerns have been raised regarding the privacy of patients who are monitored with such treatments. I propose a simple method to incorporate these concerns into a standard health impact evaluation, based on Quality Adjusted Life Years and the Incremental Cost-Effectiveness Ratio. This method provides a way to objectively value privacy concerns and balance them with health benefits. Hence, it can guide doctors and policymakers into incorporating privacy considerations and making better choices regarding e-health programs. This method can also be tested on existing economic evaluations to compare outcomes and gauge the extent to which privacy issues in medical treatments should be taken seriously.

## CONTENTS

I.	INTRODUCTION.....	2
II.	HOW MUCH IS PRIVACY WORTH.....	4
	<i>A. Experimental Literature</i> .....	4
	<i>B. We Cannot Monetize Privacy</i> .....	6
III.	COST-EFFECTIVENESS ANALYSIS OF MEDICAL INTERVENTIONS .....	7
	<i>A. Quality Adjusted Life Years</i> .....	7
	<i>B. Valuing Health States</i> .....	9
	<i>C. Incremental Cost-Effectiveness Ratio</i> .....	11
IV.	PLACING PRIVACY IN COST-EFFECTIVENESS ANALYSES .....	12
	<i>A. Quantification Based on Monetary Costs</i> .....	12
	<i>B. Quantification Based on Health States</i> .....	14
	<i>C. Methodological Questions</i> .....	15
	<i>D. How Much is a QALY Worth</i> .....	16
V.	NORMATIVE CONSEQUENCES.....	18
	<i>A. Advantages Over Alternative Methods</i> .....	18
	<i>B. How QALYs Fit the Law</i> .....	19
	<i>C. Advancing Policy Discussions</i> .....	20
	<i>D. Doctrinal Implications</i> .....	22
VI.	CONCLUSION .....	25

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## I. INTRODUCTION

With recent developments in technical means of patient surveillance, particularly involving patients under observation with distance-monitoring treatments, concerns have been raised regarding the privacy of people monitored with such treatments.<sup>1</sup> For these treatments to be operational, a significant amount of personal, and often sensitive, information about the patient is sent electronically to the medical professionals or, more frequently, to a team of people involving both medical professionals and other actors.<sup>2</sup> This information is sometimes sent together with other pieces of information, such as location data, which are not strictly necessary to treat the patient; nevertheless, the devices pick up such information.<sup>3</sup> Consequently, a relevant drawback that these treatments present is that they cause a reduction of personal privacy and an increased risk of privacy breaches. These privacy concerns are not considered at the moment of evaluating their incorporation to patient treatments.

An example of a remote patient monitoring method used by several hospitals in the U.S. is the use of electronic intensive care units (e-ICUs or tele-ICUs). Caregivers distantly monitor patients in e-ICUs through a set of cameras, microphones, other electronic monitoring systems, and smart alarms.<sup>4</sup> E-ICUs, which are among the first types of remote patient monitoring treatments, are also among the most harmless to privacy. While this healthcare platform reduces healthcare costs,<sup>5</sup> it also arguably reduces patients' privacy.<sup>6</sup> Another widespread device that is part of this category is wearable sensors. While these are usually used by caregivers to monitor patients from a distance, they are sometimes purchased directly by individuals to track their own health data as well, with no healthcare professional involved.<sup>7</sup>

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<sup>1</sup> JOHN CAREY, POWER TO THE PATIENT: HOW MOBILE TECHNOLOGY IS TRANSFORMING HEALTHCARE 2-4 (Frieda Klotz ed., 2015).

<sup>2</sup> See *id.* at 16.

<sup>3</sup> See *id.* at 10.

<sup>4</sup> Leo Celi et al., *The eICU: It's Not Just Telemedicine*, 29 CRITICAL CARE MED. N183, N184-87 (2001) (Suppl.); Brian A. Rosenfeld et al., *Intensive Care Unit Telemedicine: Alternate Paradigm for Providing Continuous Intensivist Care*, 28 CRITICAL CARE MED. 3925, 3925 (2000).

<sup>5</sup> This reduction in costs is not a minor point, as it allows for the delivery of better healthcare to a larger number of people. Consequently, the World Health Organization has endorsed mobile health as a means of expanding affordable healthcare. Alastair van Heerda et al., *Point of Care in Your Pocket: A Research Agenda for the Field of mHealth*, 90 BULL. WORLD HEALTH ORGAN. (2012).

<sup>6</sup> Celi et al., *supra* note 4, at N187.

<sup>7</sup> See GINA NEFF & DAWN NAFUS, SELF-TRACKING (2016) (explaining the increasing tendency of self-tracking health data). The Nightscout project, for example, is a startup that sells a smart watch, marketed to parents of children with diabetes, that acts as a continuous glucose monitor and provides real-time access to its data from different devices. See *Welcome to Nightscout*, THE NIGHTSCOUT PROJECT, <http://www.nightscout.info/> (last visited Aug. 21, 2016). There is a wide array of fitness trackers that work in a similar way, such as Fitbit and Jawbone. Broadly speaking, this type of practice has been called consumer health informatics. See THOMAS WETTER, INT'L MED. INFORMATICS ASS'N, WORKING GROUP CONSUMER HEALTH

E-health, which combines these methods of electronic monitoring (called remote patient monitoring or telemedicine) with internet-supported electronic health records, has raised patients' concerns.<sup>8</sup> About half of respondents in a recent survey believe that consumers' wariness about privacy violations will be a major obstacle for the adoption of mobile technology in healthcare.<sup>9</sup> In addition, over half of respondents consider privacy risks to be the biggest concern of these technologies' application to healthcare.<sup>10</sup> Moreover, the patient is not the only person whose privacy may be compromised by a telemedicine application. Home monitors, for example, also affect others in the home. Privacy concerns in e-health are of central importance to the public.

The lack of an objective way of taking privacy concerns into consideration when evaluating health policies underplays how much a loss of privacy can harm people and how much value people attribute to personal privacy. Moreover, this insufficiency is worrisome not only to privacy scholars, but also to proponents of e-health policies. Unaddressed privacy concerns can lead (and in occasions have led) to the halt of new and potentially advantageous treatments.<sup>11</sup> Harms to individual privacy, however, are difficult to observe and measure.<sup>12</sup>

This article proposes a simple way to incorporate privacy considerations into a standard health impact evaluation. Privacy concerns could be incorporated into the Quality-Adjusted Life Year framework (QALY) and the Incremental Cost-Effectiveness Ratio framework (ICER)—to which QALY can then be incorporated. QALY measures the quality and quantity of life improvements per medical treatment.<sup>13</sup> ICER measures the costs of medical treatments compared to their

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INFORMATICS REPORT AUGUST 2013 TO AUGUST 2014 (2014), [http://www.imia-medinfo.org/new2/sites/default/files/IMIA\\_WG-ConsHI\\_Rep2014.pdf](http://www.imia-medinfo.org/new2/sites/default/files/IMIA_WG-ConsHI_Rep2014.pdf).

<sup>8</sup> While there is no unified definition of e-health, all uses of the term refer to the interaction between healthcare and new technologies, especially the internet. See Hans Oh et al., *What Is eHealth (3): A Systematic Review of Published Definitions*, 7 J. MED. INTERNET RES. 1, 4-6 (2005); G. Eysenbach, *What is e-health?*, 3 J. MED. INTERNET RES. 20, 20 (2001). The two most prominent facets of this concept are remote patient monitoring and internet-supported electronic health records. This makes it narrower than health informatics or health information technology. Claudia Pagliari et al., *What Is eHealth (4): A Scoping Exercise to Map the Field*, 7 J. MED. INTERNET RES. 1, 10 (2005). For the purposes of this article, this concept includes mobile health, which involves remote patient monitoring by mobile devices. See Sofia Ranchordás & Bonnie Kaplan, *MHealth for Alzheimer's Disease: Regulation, Consent, and Privacy Concerns*, in SHLOMIT YANISKY-RAVID, *BEYOND IP: THE FUTURE OF PRIVACY* (Fordham U. Press, forthcoming 2017).

<sup>9</sup> CAREY, *supra* note 1, at 4, 14.

<sup>10</sup> *Id.*

<sup>11</sup> See *infra* Section V.C.

<sup>12</sup> See, e.g., Paul M. Schwartz & Daniel J. Solove, *The PII Problem: Privacy and a New Concept of Personally Identifiable Information*, 86 N.Y.U. L. REV. 1814, 1893 (2011); Daniel J. Solove, *"I've Got Nothing to Hide" and Other Misunderstandings of Privacy*, 44 SAN DIEGO L. REV. 745, 747, 754 (2007); Daniel J. Solove, *Conceptualizing Privacy*, 90 CALIF. L. REV. 1087, 1088 (2002).

<sup>13</sup> See Joseph S. Pliskin et al., *Utility Functions for Life Years and Health Status*, 28 OPERATIONS RES. 206, 206 (1980); Richard Zeckhauser & Donald Shepard, *Where Now for Saving Lives?*, 40 LAW & CONTEMP. PROBS. 5, 5 (1976); see also *infra* Section III.A.

effects, allowing for a comparison between treatments with different modalities.<sup>14</sup> The method proposed here estimates the dimension of privacy harms for patients and, in such a way, complements the privacy impact assessments analyses of how information is collected, stored, and disseminated.

In order to do this, this article proposes performing an estimation of the privacy-cost per treatment, contingent on the type of personal information involved. It suggests performing this estimation with a similar methodology to those used to evaluate QALY in health economics: Visual Analogue Scale, Standard Gamble, and Time-Trade-Off. These evaluation methods capture the subjective views of patients and, therefore, the patients' subjective harm. Such costs can either be used to weigh the QALY factor in itself or can be weighed together with health risks and monetary costs when evaluating the disadvantages of treatments in the ICER health impact evaluation. This application can be helpful to objectively value privacy concerns when balanced against health benefits. In doing so, it can guide policymakers into making better choices regarding e-health programs by incorporating privacy considerations when evaluating treatments. At a more abstract level, this analysis allows one to gauge the extent to which privacy should be taken seriously in e-health.

Section II of this article reviews the experimental literature that attempts to determine how much people value their privacy. Section III reviews QALY, ICER, and the tools used to measure health state valuations: Visual Analogue Scale, Standard Gamble, and Time-Trade-Off. This article suggests these methods and tools should be used to measure privacy concerns. Drawing from the previous two sections, Section IV explains how to incorporate privacy concerns in cost-effectiveness analyses; in order to do that, the section compares possible methods for evaluating privacy concerns under this framework, through monetary costs and health states. Section V presents further reasons and rationale to incorporate the proposed policy, particularly due to methodological concerns, policy considerations, and doctrinal implications. Section VI concludes this article.

## II. HOW MUCH IS PRIVACY WORTH

### *A. Experimental Literature*

The easiest way to determine how much privacy is worth would be to know the magnitude of privacy harms and add them to the social cost of any treatment. However, the experimental literature on privacy has found it extremely difficult, if not impossible, to determine how much privacy is worth. The "privacy paradox" describes the phenomenon in which people declare a high value for their private information in surveys, but in incentivized experiments, individuals disclose their information for low compensations.<sup>15</sup> The studies on how much people value their privacy show inconsistencies between declared privacy values and privacy-related

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<sup>14</sup> See Scott Ramsey et al., *Good Research Practices for Cost-Effectiveness Analysis Alongside Clinical Trials: The ISPOR RCT-CEA Task Force Report*, 8 VALUE HEALTH 521 (2005); see also *infra* Section III.C.

<sup>15</sup> Bettina Berendt et al., *Privacy in E-Commerce: Stated Preferences vs. Actual Behavior*, 48 COMM. ACM 101, 102, 104 (2005); Sarah Spiekermann et al., *E-privacy in 2nd Generation E-Commerce: Privacy Preferences Versus Actual Behavior*, in PROC. OF THE 3RD ACM CONFERENCE: ELECTRONIC COMMERCE 38, 45 (2001).

behavior online.<sup>16</sup> Privacy concerns are a weak predictor of the amount of personal information disclosed.<sup>17</sup>

Inconsistencies go beyond declared values. Independent from the inconsistencies mentioned, people display a low willingness to pay for safeguards on their personal information.<sup>18</sup> Individuals' valuations display a gap between the willingness to pay to protect information and the willingness to accept to sell information in experiments.<sup>19</sup> In surveys, the average willingness to accept payment for personal information is five times higher than the willingness to pay to protect private information (WTA:WTP ratio of 5.47).<sup>20</sup> This almost doubles the average ratio for other goods (2.92).<sup>21</sup>

Privacy valuations present some patterns, but they are scarce. People value their offline information, such as facts about themselves, three times more than online information, such as their browsing patterns.<sup>22</sup> Regarding offline information, people value the protection of undesirable traits more than that of desirable traits, even when these lead to no direct pecuniary changes.<sup>23</sup> More importantly for the topic at hand, people value information about their medical status the most, along with financial information and information about their family.<sup>24</sup>

Context is also extremely relevant for people when deciding whether to disclose information. When decisions on privacy become simpler, people tend to show a higher valuation of privacy, closer to the valuation disclosed on surveys.<sup>25</sup> In the same vein, when security settings and privacy risks are more visible, for example on

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<sup>16</sup> Spiekermann et al., *supra* note 15, at 45; Berendt et al., *supra* note 15, at 102, 104.

<sup>17</sup> Alessandro Acquisti & Ralph Gross, *Imagined Communities: Awareness, Information Sharing, and Privacy on the Facebook*, in PROCEEDINGS OF THE 6TH INTERNATIONAL CONFERENCE ON PRIVACY ENHANCING TECHNOLOGIES 36, 36 (G. Danezis & P. Golle eds., 2006); Alessandro Acquisti & Jens Grossklags, *Privacy and Rationality in Individual Decision Making*, IEEE SECURITY & PRIVACY 26, 26 (2005).

<sup>18</sup> Alastair Beresford et al., *Unwillingness to Pay for Privacy: A Field Experiment*, 117 ECON. LETTERS 25, 26-27 (2012).

<sup>19</sup> Aleecia M. McDonald & Lorrie Faith Cranor, *Beliefs and Behaviors: Internet Users' Understanding of Behavioral Advertising*, in TELECOMMUNICATIONS POLICY RESEARCH CONFERENCE 1, 25-26 (2010).

<sup>20</sup> Alessandro Acquisti et al., *What is Privacy Worth?*, 42 J. LEGAL STUD. 249, 267-68 (2013).

<sup>21</sup> *Id.* at 268.

<sup>22</sup> Juan Pablo Carrascal et al., *Your Browsing Behavior for a Big Mac: Economics of Personal Information Online*, in PROCEEDINGS OF THE 22ND INTERNATIONAL CONFERENCE ON WORLD WIDE WEB 189, 189 (2013).

<sup>23</sup> Bernardo Huberman et al., *Valuating Privacy*, 3 IEEE SECURITY & PRIVACY 22, 22 (2005).

<sup>24</sup> Daniel Horne & David Horne, *Domains of Privacy: Toward an Understanding of Underlying Factors*, in DIRECT MARKETING EDUCATORS' CONFERENCE (1998).

<sup>25</sup> Luc Wathieu & Allan Friedman, *An Empirical Approach to Understanding Privacy Valuation* 1-6 (Harvard Bus. Sch., Working Paper No. 07-075, 2007).

internet browsers, people react with an increased protection of their information.<sup>26</sup> People value having control over the publicity of their personal information.<sup>27</sup> However, in the medical context, at least for mobile applications, it is rarely the case that privacy policies make privacy concerns visible.<sup>28</sup>

### *B. We Cannot Monetize Privacy*

This risk of privacy breaches represents the disutility of any use that can be made with the traded information that is unpleasant to the person; hence, an individual should take it into account as an expected cost when deciding whether to disclose. Therefore, the materialization of such risk can take many forms, the most common ones ranging from mostly harmless annoyances, such as receiving spam email, to more serious consequences, such as public disclosure of embarrassing information or the acquisition of information by medical insurers or future employers that would financially damage the person, identity fraud, or identity theft.

When data controllers trade someone's personal information, that person has an increased risk of suffering a privacy breach.<sup>29</sup> The user will have his or her personal data out of his or her range of control, but its use by others still has the potential of impacting the individual's welfare negatively, which means that there are externalities in data trading. These externalities imply an incentive for other actors to overuse the information.<sup>30</sup> An example of actors that can impact a person's welfare can be advertising companies, social networks, or, in the case of medical data, medical professionals and insurance companies.

Moreover, people care not only about direct harm, but also about the indirect consequences that the transmission of their personal information can imply, particularly about how their information will be used, even if it will have no direct consequences for them (such as spam, fraud, or identity theft).<sup>31</sup>

As observed, people's reactions to privacy decisions change depending on a particular decision's complexity.<sup>32</sup> When information about privacy threats becomes visible, people sometimes respond to the threat by choosing higher privacy

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<sup>26</sup> Julia Gideon et al., *Power Strips, Prophylactics, and Privacy, Oh My!*, in PROCEEDINGS OF THE SECOND SYMPOSIUM ON USABLE PRIVACY AND SECURITY 133-40 (2006); Janice Tsai et al., *The Effect of Online Privacy Information on Purchasing Behavior: An Experimental Study*, 22 INFO. SYS. RES. 254, 263 (2011); Victoria Groom & Ryan Calo, *Reversing the Privacy Paradox: An Experimental Study*, in TELECOMMUNICATIONS POLICY RESEARCH CONFERENCE 1-9 (2011).

<sup>27</sup> Leslie John et al., *Strangers on a Plane: Dependent Willingness to Divulge Sensitive Information*, 37 J. CONSUMER RES. 858, 859 (2011).

<sup>28</sup> Ali Sunyaev et al., *Availability and Quality of Mobile Health App Privacy Policies*, 22 J. AM. MED. ASS'N 28, 28 (2015).

<sup>29</sup> John Hagel & Jeffrey Rayport, *The Coming Battle for Consumer Information*, 75 HARV. BUS. REV. 53, 53 (1997).

<sup>30</sup> Peter Swire & Robert Litan, *None of Your Business: World Data Flows, Electronic Commerce and the European Privacy Directive*, 12 HARV. J. L. & TECH. 683, 684 (1998).

<sup>31</sup> Wathieu & Friedman, *supra* note 25, at 7.

<sup>32</sup> *Id.* at 2; John et al., *supra* note 27, at 268.

protections.<sup>33</sup> Many times, people do not understand privacy policies and license agreements<sup>34</sup> and the available privacy protection tools.<sup>35</sup> Protecting privacy requires technical skills that few people have.<sup>36</sup> This necessity can largely explain the contradicting results of the experimental literature and the difficulties in identifying a single monetary value for privacy.<sup>37</sup>

For this reason, if personal data are treated equally in experimental settings and security settings and privacy risks are not visible, contradicting results might be reached.<sup>38</sup> This issue highlights the usefulness of the proposal made in this article, which focuses on visibility and one particular type of personal information: health data.

### III. COST-EFFECTIVENESS ANALYSIS OF MEDICAL INTERVENTIONS

#### A. Quality Adjusted Life Years

In the face of limited budgets for healthcare spending and multiple potential treatments that could be funded, the use of Cost-Effectiveness Analysis (CEA) has become widespread in medical decision-making.<sup>39</sup> For example, the National Institute for Clinical Excellence in England, the body responsible for offering guidance on the medical spending of public funds, has fully embedded the CEA methodology into its decision-making processes.<sup>40</sup> CEA is a formal procedure based on estimations of the costs and benefits of each treatment. Its fundamental idea is to choose health interventions that offer the greatest benefit for the smallest costs. In the simplest case, if treatment *A* cures a condition at cost *x* and treatment *B* cures it at cost *y*, and  $y < x$ , then treatment *B* is preferred over treatment *A*.

Several problems arise when comparing health outcomes across potential treatments. Perhaps most importantly, one must determine how to compare the outcomes of two different health technologies that affect different aspects of a patient's health. For example, one medication may lower cholesterol levels while another may provide pain relief. These two medicines would be difficult to compare along a single scale.

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<sup>33</sup> Gideon et al., *supra* note 26, at 142; Tsai et al., *supra* note 26, at 254.

<sup>34</sup> George Milne & Mary Culnan, *Strategies for Reducing Online Privacy Risks: Why Consumers Read (or Don't Read) Online Privacy Notices*, 18 J. INTERACTIVE MARKETING 15, 23 (2004).

<sup>35</sup> Acquisti & Grossklags, *supra* note 17.

<sup>36</sup> Joseph Turow, *Americans and Online Privacy: The System is Broken*, ANNENBERG PUB. POL'Y CTR. U. PA. 25 (2003).

<sup>37</sup> Ignacio Cofone, *The Value of Privacy: Keeping the Money Where the Mouth Is 1-5* (Rotterdam Inst. Law & Econ., RILE Working Paper No. 2014-15, 2015).

<sup>38</sup> Wathieu & Friedman, *supra* note 25, at 2.

<sup>39</sup> David O. Meltzer & Peter C. Smith, *Theoretical Issues Relevant to the Economic Evaluation of Health Technologies*, in 2 HANDBOOK OF HEALTH ECONOMICS 433-34 (Mark V. Pauly et al. eds., 2011).

<sup>40</sup> S. Bryan et al., *Seeing the NICE Side of Cost-Effectiveness Analysis: A Qualitative Investigation of the Use of CEA in NICE Technology Appraisals*, 16 HEALTH ECON. 179, 179 (2007).



In order to rank treatments on a comparable scale, researchers use the concept of QALYs.<sup>41</sup> A QALY represents the value of living one year in a perfect health condition, and this baseline is used as a proxy for the quality of one's life during that year.<sup>42</sup> To be precise, the benefit of a particular treatment is translated into the gain in QALYs that the treatment is expected to provide. *Quality-adjusted* life-years are used, rather than simply life-years, in order to account for the fact that both the duration and quality of an individual's life matter. In our example of pain-lowering and cholesterol-lowering medications, while the cholesterol medication may extend life by three more years, the improved quality of life offered by the reduction in pain might give us a reason to favor this intervention instead.

Quality of life or health status is typically scored between 0 and 1, with 0 representing death and 1 representing perfect health.<sup>43</sup> Consider a person who will live during a four-year timespan with a health status scored at 0.5. During those four years, this individual will have experienced two QALYs. Since a QALY represents a year lived in perfect health, this four-year window is considered the equivalent of living two years in perfect health. An example of the QALYs that a standard person has over a lifetime is shown below in Figure 1. As an individual's age increases, especially in advanced years, his or her health status falls. In this example, the individual lived  $T$  years. The individual's QALYs for each year are equal to the shaded area under the curve, which will obviously be smaller than 1 and will reach 0 at time  $T$ .

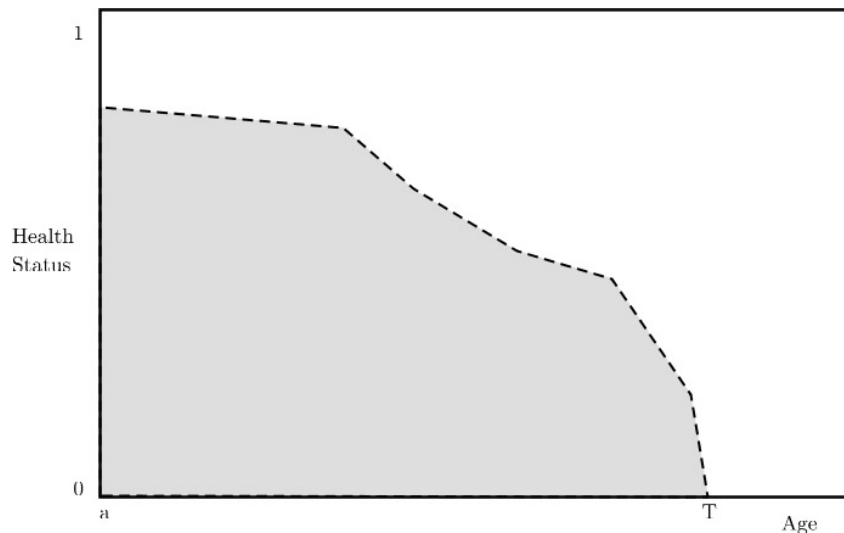


Figure 1: Example of QALYs over a lifetime

<sup>41</sup> Meltzer & Smith, *supra* note 39, at 439; J. Brazier et al., *A Review of the Use of Health Status Measures in Economic Evaluation*, 3 HEALTH TECH. ASSESSMENT 1, 3 (1999).

<sup>42</sup> Brazier et al., *supra* note 41; Paul Dolan, *The Measurement of Health Related Quality of Life for Use in Re-Source Allocation Decisions in Health Care*, in 1B HANDBOOK OF HEALTH ECONOMICS 1723-26 (A.J. Culyer & J.P. Newhouse eds., 2000).

<sup>43</sup> Dolan, *supra* note 42, at 1726.

The next question that naturally arises is how one can quantitatively measure a person's quality of life. The topic of measuring health utilities, as well as more general utilities, has been largely debated in health economics.<sup>44</sup> In practice, three main tools are used to elicit health utility scores: Visual Analogue Scale, Standard Gamble, and Time Trade-off.<sup>45</sup>

### B. Valuing Health States

A vital step in CEA is the valuation of health states, which allows the calculation of QALYs. The three main tools used to elicit these health utility scores are the Visual Analogue Scale, the Standard Gamble, and the Time-Trade-Off. Each method begins with the description of the health state that the researcher needs to value.<sup>46</sup> In order for the results to be as generalizable as possible and to avoid any preconceptions about certain illnesses, the description is usually very general. Rather than naming actual conditions or diseases, health states are often given in terms of several different "dimensions" of health and well-being, such as mobility, self-care, ability of perform everyday tasks, pain or discomfort, and mental health.<sup>47</sup> An example of a health state is given in Box 1.

<u>Health State A</u>
<ul style="list-style-type: none"> <li>• You have poor mobility</li> <li>• You have some problems washing and dressing yourself</li> <li>• You have some problems with performing your usual activities</li> <li>• You experience moderate pain or discomfort</li> <li>• You are not anxious or depressed</li> </ul>

Box 1: Example of a health state

The Visual Analogue Scale simply asks individuals to pinpoint visually on a scale from 0 to 100 how much they would value the health state described above, where 0 is equivalent to death and 100 is equivalent to perfect health.<sup>48</sup> The average value pointed by individuals is then directly translated to QALYs. An example of the Visual Analogue Scale is depicted in Box 2 below.<sup>49</sup>

<sup>44</sup> See generally ECONOMIC EVALUATION IN HEALTH CARE: MERGING THEORY WITH PRACTICE (M.F. Drummond & A. McGuire eds., 2001) (discussing theoretical underpinnings of economic evaluations of health care).

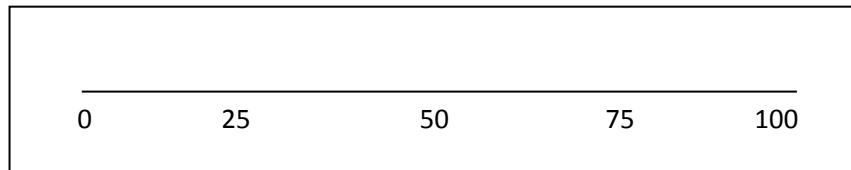
<sup>45</sup> Paul Dolan & Matthew Sutton, *Mapping Visual Analogue Scale Health State Valuations onto Standard Gamble and Time Trade-off Values*, 44 SOC. SCI. MED. 1519, 1519 (1997). These methods are further explained in the following subsection.

<sup>46</sup> Paul Dolan et al., *Valuing Health States: A Comparison of Methods*, 15 J. HEALTH ECON. 209, 210 (1996).

<sup>47</sup> *Id.* at 215; Dolan & Sutton, *supra* note 45, at 1519, 1521.

<sup>48</sup> David Parkin & Nancy Devlin, *Is There a Case for Using Visual Analogue Scale Valuations in Cost-Utility Analysis?*, 15 HEALTH ECON. 653, 655 (2006).

<sup>49</sup> The line is often portrayed vertically, although this is not uniform.



Box 2: Visual Analogue Scale

In a Standard Gamble, on the other hand, people compare two situations, the described health state and perfect health in order to elicit from their answer their perceptions on the relative merit of those situations.<sup>50</sup> The QALY value is established by the lowest probability of living in perfect health that people consider to be high enough to take the treatment that “cures” them from the described health state.<sup>51</sup> For example, if patient *A* is indifferent between living with chronic migraines and taking a treatment that will (i) cure his or her migraines with a probability of 95% and (ii) cause death with a probability of 5%, then the QALY value of the treatment is 0.95. The Standard Gamble method presents individuals with a described scenario such as the following:<sup>52</sup>

*“Imagine you are currently experiencing health state A. There is a treatment available that, if successful, will allow you to return back to perfect health. The treatment has probability p of being successful. However, there is probability 1-p that the treatment fails and kills you. At what probability (p) would you be indifferent between taking the treatment and not taking the treatment?”*

Box 3: Standard Gamble

Mathematically, one tries to elicit the following equality from the individual.

$$U(H_A) = p(U(H_{Full\ Health})) + (1 - p)(U(H_{Death}))$$

Where  $U(\cdot)$  is the individual’s utility function. Given that  $U(H_{Full\ Health}) = 1$  and  $U(H_{Death}) = 0$ , the utility of  $H_A$  is then given by  $p$ . The intuition behind this is that, if someone under the described health state would be willing to risk death with a probability of 5% to obtain perfect health for a year, then that health state is for them 95% as good as perfect health.

The Time-Trade-Off method, in turn, takes time into account. In this method, respondents make a choice similar to that of the Standard Gamble, but among a number of years in perfect health ( $X$ ) versus a number of years with the health problem ( $Y$ ), and the ratio among them ( $X:Y$ ) determines the QALY value.<sup>53</sup> If the

<sup>50</sup> Brazier et al., *supra* note 41, at 37.

<sup>51</sup> Milton C. Weinstein et al., *QALYs: The Basics*, 12 *VALUE HEALTH* 55, 55, 58 (2009).

<sup>52</sup> *Id.* at 57.

<sup>53</sup> *Id.*

patient *A* from the example above is indifferent between living for 50 more years with migraines and living 40 more years in perfect health, then the QALY value of the treatment is 0.8. Time-Trade-Off presents individuals with a scenario such as the following:<sup>54</sup>

*“Imagine you are currently experiencing health state A. You are given the following choice. You can either continue to live in health state A for 10 years, at which point you will die. Alternatively, you can give up some of these 10 years and live n years in perfect health (where n<10). At what number of years (n) would you be indifferent between the two*

Box 4: Time Trade-off

Mathematically:

$$U(H_A) * 10 = U(H_{Full\ Health}) * n$$

Again, given that  $U(H_{Full\ Health}) = 1$ , the utility of  $H_A$  is then given by  $n/10$ .

In this way, QALYs can, albeit imperfectly, quantify dimensions of different health states and diverse treatments, such as pain, that are otherwise unquantifiable. QALYs give policymakers and health professionals a framework to take these dimensions into account and evaluate treatments more accurately without disregarding either the dimension or the treatment.

### C. Incremental Cost-Effectiveness Ratio

Once a program’s benefits have been translated into gains in QALYs, the ICER is calculated.<sup>55</sup> This ratio measures the *incremental* cost of the *incremental* gain of program *A* compared with program *B*.<sup>56</sup> In the formula below,  $Q_a$  and  $Q_b$  are the QALY values associated with programs *A* and *B*, respectively, and  $C_a$  and  $C_b$  are the costs associated with them.

$$ICER = \frac{Q_a - Q_b}{C_a - C_b}$$

In practice, new programs are compared to the “usual care” of patients who are targeted by the treatment.<sup>57</sup> In the representation above, the usual care would be program *A*. In the example of a new cholesterol medication, the new treatment would be compared to the medication that is currently used to lower cholesterol. If a medication were completely novel, in the sense that it is designed to treat a condition for which there currently exists no standard treatment, the comparison parameter would be “no care.”<sup>58</sup>

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<sup>54</sup> *Id.*

<sup>55</sup> Andrew H. Briggs et al., *Pulling Cost-Effectiveness Analysis up by Its Bootstraps: A Non-Parametric Approach to Confidence Interval Estimation*, 6 HEALTH ECON. 327, 327 (1997).

<sup>56</sup> *Id.*

<sup>57</sup> Meltzer & Smith, *supra* note 39.

<sup>58</sup> *Id.*

ICER can be thought of as the dollar cost per each additional QALY point when moving from treatment *A* to *B*. Decision-makers can therefore use ICER values to select the most cost-effective treatments. The lower the ICER value is, the more cost-effective the treatment is compared to others that achieve equivalent results.

If there is a given healthcare budget to spend, programs can be ranked inversely in terms of their ICER values and implemented until the budget is depleted, thereby maximizing health benefits within a given budget constraint. An alternative approach in the situation where there is no budget constraint is to compare each ICER to a threshold value that can be thought of as the maximum amount that a government is willing to spend on each additional QALY.

#### IV. PLACING PRIVACY IN COST-EFFECTIVENESS ANALYSES

##### *A. Quantification Based on Monetary Costs*

To operationalize the proposed change, it is theoretically possible to embed privacy concerns into either the numerator or the denominator of the ICER equation—which is the ratio of the change in QALYs and in the costs of an intervention. Given these considerations, there seem to be two ways to incorporate privacy concerns into ICER evaluations. The first way to incorporate privacy concerns is to include privacy in the costs of health treatments. The second is to include privacy concerns as a moderating element in the benefit section of ICER evaluations—that is, within QALYs themselves.

Incorporating privacy issues as part of the monetary costs of a medical intervention is an intuitive idea. After all, by virtue of presenting privacy disutilities or potential privacy harms to patients who are being monitored, e-health treatments have an extra cost, even if non-monetary. If one cares about the well-being of those patients or about social welfare, there is no reason why, at the moment of evaluating the costs of these treatments, one should take into account the costs of treatments for hospitals but not the costs for patients themselves.

However, incorporating privacy concerns in the cost section of ICER evaluations presents the obstacle of the indeterminacy of the privacy concerns' monetization. Monetizing privacy, as illustrated in Section II's review of the experimental literature, is at best a difficult task.<sup>59</sup> Surveys and experiments have given inconsistent results regarding how much to value privacy.<sup>60</sup> More importantly, experiments with different designs have given inconsistent values among themselves, so one cannot attribute the inconsistency to a dissonance between declared and revealed preferences.<sup>61</sup>

There are ways to partially, although not totally, overcome the problem of the indeterminacy of the privacy concerns' monetization. The lessons learned from the experimental literature allow researchers to perform new experiments that are restricted to the context of e-health in particular. These new, restricted experiments could potentially give more accurate values for personal information, albeit still approximate, that could help implement privacy concerns. To do this, two chief issues should be kept in mind: the variable value of different types of information and the effects of privacy risk awareness.

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<sup>59</sup> See *supra* Section II.

<sup>60</sup> Acquisti et al., *supra* note 20, at 251-52.

<sup>61</sup> See *supra* Section II.

The first lesson from the literature is that people value different kinds of information differently, so estimations on the value of information cannot be made on abstract notions such as “privacy” or “personal information.” Rather, they must be narrower. Sub-categories, such as “offline information” or “sensitive information,” are already a step in the right direction, but the use of sub-categories is likely insufficient to acquire useful results, as the sub-categories still include various types of information that people could value differently. In this way, one could conduct experiments regarding different kinds of information that are necessary for different treatments under evaluation. Location data is a good candidate because it is specific enough for people to have a realistic representation of it during the experiment, and this type of data is included in several e-health treatments.

The second lesson from the stream of literature is that privacy concerns are not always visible in experimental designs. Because privacy concerns are not always visible in experimental designs, they may lead to results that point to very low privacy valuations. The showing of low privacy valuations does not necessarily result because people actually attributed little value to the type of personal information involved, but it can also result because the individuals were not fully aware of the risks that the disclosure involved. If experiments are run in the context of e-health, they should make sure that the privacy costs involved are visible to the subjects.

Keeping the two lessons garnered from the literature in mind, it is possible to run incentivized experiments specifically aimed at arriving at a monetary price for privacy concerns related to different types of health data. The very nature of health data might make it easier to tackle both of the lessons mentioned and conduct experiments with specific types of personal information and visible privacy costs. Experiments gauging the value of privacy in e-health, from this perspective, could also potentially shed more light onto the “privacy paradox.”

It would be difficult to know in advance if the experiments gauging the value of privacy in e-health would give higher or lower valuations than those conducted previously because two effects that run in opposite directions are present. On one hand, decisions in e-health typically include more sensitive information than decisions in shopping simulations. One may expect individuals to become sensitive regarding their private information when it consists of data regarding medical history. In expectation, an individual’s privacy is more reduced when facing a data leak regarding information about one’s potential diseases than when facing a leak regarding one’s shopping patterns, even if the latter could also lead in turn to more sensitive information. The distinction between health information and information regarding standard shopping patterns could lead people to disclose less than average in privacy-related experiments.

On the other hand, decisions in e-health typically have a larger trade-off than decisions in shopping simulations. The health benefits that e-health treatments provide over standard treatments are, on average, significantly more valuable than the shopping discounts used in traditional privacy experiments. It is not equally beneficial to reduce one’s possibility of having a heart attack or appropriate maintenance of a lupus condition than having the ability to save a few dollars when purchasing a blow dryer. This difference in long-term benefits could lead people to choose to disclose more information in the e-health context.

If such experiments did indeed give sensible and theoretically consistent estimates of the monetary costs of the reduction of privacy that an e-health treatment implies, it would become a relatively simple task to include these values in ICER

ratios. The only task to be performed would be to add the experimentally estimated monetary costs of privacy to the  $C_a$  and  $C_b$  values in the denominator of the ICER ratio. There is, however, a simpler and cheaper way to quantify privacy concerns in e-health treatments.

### *B. Quantification Based on Health States*

Monetizing privacy concerns would be difficult even with the best practices described. For this reason, this article proposes an alternative valuation method: embedding privacy costs within QALYs. Privacy costs can be embedded within the numerator, not the denominator, of the ICER ratio. This would imply using slightly altered versions the Health States measured by the Visual Analogue Scale, Standard Gamble, and Time-Trade-Off methods.

To accomplish the task of embedding privacy costs within QALYs, a probability of the data becoming public can be included in the descriptions of the health states on which the Visual Analogue Scale, Standard Gamble, and Time-Trade-Off operate. Imagine that a new medical intervention is available for a particular illness. This intervention (intervention *A*) raises a patient's health from  $H_b$  to  $H_a$  (where  $H_a > H_b$ ). However, the intervention also involves continuous external collection of the patient's sensitive data, such as heart rate and location. In order to assess the utility of this treatment, the privacy concerns of patients should be taken into account. And a slight alteration of the traditional Visual Analogue Scale, Standard Gamble, and Time-Trade-Off methods can easily measure patients' privacy concerns. As before, each of these methods would begin with description of the health state under inspection,  $H_a$ . However, in addition to the traditional "dimensions" of health, the health state would also describe the data being collected, state who has access to the data, and estimate the risk level ( $r$ ) of a data breach. Box 5 illustrates the suggested health state description.

<u>Health State A'</u>
<ul style="list-style-type: none"> <li>• You have poor mobility</li> <li>• You have some problems washing and dressing yourself</li> <li>• You have some problems with performing your usual activities</li> <li>• You experience moderate pain or discomfort</li> <li>• You are not anxious or depressed</li> <li>• Data on your heart rate is being collected</li> <li>• Data on your location is being collected</li> <li>• Your doctor and other employees of the hospital have access to these data</li> <li>• There is a 2% risk (<math>r</math>) that the data becomes publicly available</li> </ul>

Box 5: Modification of health state description

After presenting this altered version of health state *A*, its valuation would then continue as before. The resulting valuation of this health state, however, would give an estimate of the utility of being in health state *A* in addition to having the

corresponding level of privacy. In other words, utility levels elicited through the proposed method, and the resulting QALYs, would incorporate the individual's privacy concerns. In such a way, the QALYs would present a more complete picture of the monetary and non-monetary costs of the medical intervention.

The initial step in valuing privacy concerns in this way could take place in an un-incentivized experimental setting. Two groups of individuals would be given Visual Analogue Scale, Standard Gamble, and Time-Trade-Off questions. One of them would be faced with a health state description without the modifications specified above in Box 5, and one of them would see the health state with these modifications. If the privacy risks involved in data collection and storage are seen by patients as a significant disutility in the context of healthcare, then one would expect the average utility of patients under the modified health state ( $A'$ ) to be lower than the utility of the group facing the unmodified health state ( $A$ ). The results of the valuation in both groups would serve as an initial comparison. They would give an indication of the value placed by patients on that type of loss of that particular kind of personal information for that health benefit. Any large disparities between the modified health state and the non-modified health state might indicate that the ranking of programs based on traditional CEA methods does not represent true preferences.

### *C. Methodological Questions*

There is ongoing debate as to which of the methods to estimate QALYs mentioned in the previous section gives the most accurate results.<sup>62</sup> For example, while the Visual Analogue Scale is intuitively simple and quick to perform, some have suggested that the method may suffer from various biases.<sup>63</sup> Individuals often avoid the extremes of the scale, leading to clustering around the middle values. From this perspective, Standard Gamble and Time Trade-Off are more robust. Between Standard Gamble and Time Trade-off, it has been suggested that Time-Trade-Off is generally more robust,<sup>64</sup> although this conclusion largely depends on the concrete versions. Different valuation techniques can also perform better in different contexts.<sup>65</sup>

The inclusion of privacy harm as an extra measure would probably not alter the considerations regarding the issue of which of these valuation techniques is more appropriate. Privacy concerns would need to be incorporated into each of the valuations performed with these techniques without altering the considerations that determine the choices among them.

Still, there are obstacles to these alterations of the Visual Analogue Scale, Standard Gamble, and Time-Trade-Off methods. The first obstacle is that introducing a new variable and dimension into the elicitation technique in the form of privacy concerns would increase its complexity and could potentially confuse participants, resulting in less accurate measurements.

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<sup>62</sup> Erik Nord, *Methods for Quality Adjustment of Life Years*, 34 SOC. SCI. MED. 559, 560 (1992).

<sup>63</sup> Parkin & Devlin, *supra* note 48.

<sup>64</sup> Han Bleichrodt & Magnus Johannesson, *Standard Gamble, Time Trade-Off and Rating Scale: Experimental Results on the Ranking Properties of QALYs*, 16 J. HEALTH ECON. 155, 156 (1997).

<sup>65</sup> Nord, *supra* note 62, at 559-60.



To address the first obstacle, researchers would have to carefully design elicitation techniques that avoid scenarios that are too complex. Even if this modification is necessarily more intricate than health descriptions without privacy concerns, the same argument can be made for any measurement that is incorporated in the health state to measure patients' well-being, such as anxiety or inability to perform daily tasks. In turn, one of the advantages of this elicitation technique compared to standard ways to measure privacy concerns is the visibility of the comparable health states. Even if the elicitation technique with privacy concerns is more complex than the same technique without them, it is still simpler than the alternative methods to measure these same concerns.

The main potential obstacle in implementing this proposal is that including the privacy concerns in the utility calculations would increase the amount of data collection that a researcher would be required to perform. Currently, there are tables produced by research groups that conveniently list the utilities of health states at different dimensions of health, derived from a representative sample of a given population.<sup>66</sup> Using the above methods, researchers would no longer be able to use these values directly and would instead have to collect data and administer the elicitation techniques themselves. Consequently, widespread use of this method may be costly unless the most commonly used databases of health utilities incorporate the method.

If the obstacle to implementing the proposal turns out to be significant, it could be an interesting alternative to repeat the QALY estimation and ICER calculation on a few existing treatments with the inclusion of the altered elicitation techniques in order to get an impression of how the ICER values would change in each case.

#### *D. How Much is a QALY Worth*

In developed countries, the ICER values for new treatments—the cost for public health policies for increasing one QALY—typically lie between \$50,000 and \$200,000, depending on context.<sup>67</sup> ICER is usually compared to the lower bound of that range, approximately \$50,000.<sup>68</sup> An ICER value below this amount is thought to be good value for money. While this value is useful as a starting point, a large amount of literature is aimed at determining a more accurate threshold that reflects the value that society places on a QALY, rather than how much is usually spent on one. If a convincing estimate can be made for this value, then all programs with an ICER value below this point, which can give a person one quality adjusted life year at a lower social cost, should be funded.

The standard alternative approach to ICER has been to derive a value using traditional willingness-to-pay methodology, which has reached widely varied

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<sup>66</sup> The most frequently used database of health utilities is the EQ-5D, produced by the EuroQol Group. The database uses five dimensions to separate health states: mobility, self-care, usual activities, pain or discomfort and anxiety or depression. Another method is HUI3, which uses eight dimensions: vision, hearing, speech, ambulation, pain, dexterity, cognition, and emotional state. See Brazier et al., *supra* note 41.

<sup>67</sup> CAM DONALDSON ET AL., EUROPEAN VALUE OF A QUALITY ADJUSTED LIFE YEAR 32-33 (2011).

<sup>68</sup> Richard A. Hirth et al., *Willingness to Pay for a Quality-Adjusted Life Year in Search of a Standard*, 20 MED. DECISION MAKING 332, 332-33 (2000).

estimations.<sup>69</sup> Some research based on the willingness-to-pay methodology has valued QALYs at an average of €306,000 (\$346,160) for thirty-five estimates.<sup>70</sup> However, most research has found lower monetary estimations for the willingness to pay for QALYs, closer, but still higher, than the lower bound of ICER values. In the European Union, a EuroVaQ report covering ten representative European countries reached an average willingness to pay of €65,000 (\$73,510) per QALY.<sup>71</sup> A study surveying the literature on the topic has found that most estimations range between €100,000 and €150,000 (\$113,000 and \$169,700) per QALY.<sup>72</sup> If these studies are accurate, they seem to indicate that people value QALYs, on average, at higher values than what is socially spent on them.<sup>73</sup>

Another alternative approach can be found in Value of Statistical Life research, which is one of the most prominent examples of an objective measure of willingness to pay to avoid immaterial losses. The Value of Statistical Life literature attempts to monetize the probability of (essentially non-monetary) fatal accidents by asking how much a potential victim would be willing to pay to avoid facing a risk.<sup>74</sup> When people engage in dangerous behavior, such as buying a risky product or performing a risky job, they are implicitly making a trade-off between money and their own safety. This choice would allow for estimating the value that they place on their own lives or their own characteristics, assuming perfect rationality and information. An aggregation of those values can in return provide the statistical value of a life.<sup>75</sup>

Most of the losses that the Value of Statistical Life literature considers are non-pecuniary losses,<sup>76</sup> which encompass losses that are non-monetary; accordingly, a monetary compensation cannot always leave the victim equally well-off.<sup>77</sup> Since a loss in privacy is, in essence, non-pecuniary,<sup>78</sup> this method could be well equipped in dealing with its abstract nature.

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<sup>69</sup> *Id.* at 332.

<sup>70</sup> *Id.* at 338.

<sup>71</sup> CAM DONALDSON ET AL., *supra* note 67.

<sup>72</sup> See Don Kenkel, *WTP- and QALY-Based Approaches to Valuing Health for Policy: Common Ground and Disputed Territory*, 34 ENV'T. & RESOURCE ECON. 419 (2006).

<sup>73</sup> Additionally, this would suggest that more money could be spent in public healthcare before reaching people's average willingness to pay for health benefits.

<sup>74</sup> See W. Kip Viscusi & Joseph E. Aldy, *The Value of a Statistical Life: A Critical Review of Market Estimates Throughout the World* (Nat'l Bureau of Econ. Research, Working Paper No. 9487, 2003), <http://www.nber.org/papers/w9487>.

<sup>75</sup> See W. Kip Viscusi, *The Flawed Hedonic Damages Measure of Compensation for Wrongful Death and Personal Injury*, 20 J. FORENSIC ECON. 113 (2007); Eric A. Posner & Cass R. Sunstein, *Dollars and Death*, 72 U. CHI. L. REV. 537 (2005); Cass R. Sunstein, *Lives, Life-Years, and Willingness to Pay*, 104 COLUM. L. REV. 205 (2004).

<sup>76</sup> See Ted R. Miller, *Willingness to Pay Comes of Age: Will the System Survive?*, 93 NW. U. L. REV. 876 (1989) [hereinafter Miller, *Willingness to Pay*].

<sup>77</sup> Louis Visscher, *Time is Money? A Law and Economics Approach to 'Loss of Time' as Non-Pecuniary Loss*, 5 J. EUR. TORT L. 35, 35-36 (2014) [hereinafter Visscher, *Time is Money?*].

<sup>78</sup> When a person faces a privacy violation, his reduction in utility cannot be fully repaired by a monetary compensation. The compensation can attempt to increase his utility to leave

The value of QALYs has not been estimated with the Value of Statistical Life approach. However, one could expect the Value of Statistical Life approach to value QALYs much higher than the willingness-to-pay methodology. This is because the Value of Statistical Life methods consider both material and immaterial losses, while QALY only considers immaterial losses.<sup>79</sup>

## V. NORMATIVE CONSEQUENCES

### A. Advantages Over Alternative Methods

There are several reasons why capturing privacy concerns in QALYs would be superior to the other available methods. Life states are goods more easily comparable between each other than are privacy versus monetary benefits. Consequently, individuals would better grasp the value of their private information and, therefore, the value of their privacy, when it is presented in a trade-off between different health states, as opposed to a trade-off between privacy and money. It is difficult for people, both in surveys and in a laboratory, to allocate a monetary value to something as abstract as privacy. But it is possible for individuals to compare two concrete and plausible life states and decide which one they prefer. In such a way, the method combines the best features of the surveys and experiments performed in the past in order to quantify privacy concerns. Like the experiments, it presents people with a trade-off that can elicit more precise answers than abstract questions. Like the surveys, it makes privacy issues more visible.

Additionally, eliciting privacy concerns via comparisons between health states is highly relevant in the particular context of privacy issues raised by the collection of data by e-health treatments. The valuations obtained with the method proposed here will allow policymakers to directly measure the patient's privacy costs in the context of health states, eliminating the intermediate step of applying general privacy valuations to the medical context. Compared to methods that rely on monetization, the method proposed here presents a much more direct way of measuring privacy concerns associated with medical interventions.

Further, the proposed method can be altered to determine which types of collection methods and treatment-associated risks individuals are most responsive. The proposed method may be repeated with varying values of  $r$  to assess the sensitivity of the individual to different probabilities of data breach. For example, it may be the case that until a certain risk occurs, people are indifferent to a potential data leak.<sup>80</sup> A further informative alteration to the method would be to change the type of data being collected. This modification would allow for measurements of how much more people value certain types of personal data over others. For

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him in a similar position as the one he was before, but it can never leave him in exactly the same position.

<sup>79</sup> Vaia Karapanou & Louis Visscher, *The Magnitude of Pain and Suffering Damages from a Law and Economics and Health Economics Point of View* (Rotterdam Inst. L. Econ. Working Paper No. 2009/02, 2009), <http://ssrn.com/abstract=1327793> [hereinafter Karapanou & Visscher, *Magnitude of Pain*].

<sup>80</sup> This could be expected given people's non-linear assessments of probabilities. See Daniel Kahneman & Amos Tversky, *Prospect Theory: An Analysis of Decision Under Risk*, 47 *ECONOMETRICA* 263 (1979); Daniel Kahneman & Amos Tversky, *Choices, Values and Frames*, 39 *AM. PSYCHOL.* 341, 341 (1983).

instance, one can expect that preferences elicited based on collection of a patient's heart rate would be lower than those based on the collection of sexually transmitted infections histories.

### B. How QALYs Fit the Law

There are two further reasons to incorporate the policy suggestion made here. One reason to incorporate it is that QALYs were shown to be fitting to quantification in law.<sup>81</sup> Another reason is that the proposal fits with the reason why CEA and QALYs exist in the first place.

The use of QALYs has been proposed in other areas to guide legal valuations on losses of quality of life.<sup>82</sup> Their use has been suggested to estimate damages based on detailed and tailored scales in jury trials<sup>83</sup> and within more general approaches that incorporate QALYs in tort law as a tool to quantify pain and suffering damages.<sup>84</sup> The tort use of the metric includes the possibility of considering QALYs as a way to estimate the value of loss of time.<sup>85</sup> The fundamental idea behind this approach is that the extent to which tort law should compensate victims can be measured by how much they would have been willing to pay to prevent those losses in the first place when evaluated from an ex-ante perspective.<sup>86</sup>

QALYs provide a more objective way to compare different kinds of immaterial losses.<sup>87</sup> The more objective nature of QALYs makes them fitting to quantify immaterial losses in fields where this quantification would be helpful, or even necessary, to take these losses into account. The estimation of damages in tort law and the evaluation of treatments in public health policy, particularly within the CEA

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<sup>81</sup> Ted R. Miller, *Valuing Nonfatal Quality of Life Losses with Quality-Adjusted Life Years: The Health Economist's Meow*, 13 J. FORENSIC ECON. 145, 145 (2000) [hereinafter Miller, *Valuing Nonfatal Quality*].

<sup>82</sup> Vaia Karapanou & Louis Visscher, *Towards a Better Assessment of Pain and Suffering Damages*, 1 J. EUR. TORT L. 48, 48, 55 (2010) [hereinafter Karapanou & Visscher, *Better Assessment of Damages*].

<sup>83</sup> Miller, *Willingness to Pay*, *supra* note 76.

<sup>84</sup> See Karapanou & Visscher, *Better Assessment of Damages*, *supra* note 82, at 48; Karapanou & Visscher, *Magnitude of Pain*, *supra* note 79; Vaia Karapanou & Louis Visscher, *Quality Adjusted Life Years as a Way Out of the Impasse between Prevention Theory and Insurance Theory* (Rotterdam Inst. L. Econ. Working Paper No. 2010/06, 2010), <http://dx.doi.org/10.2139/ssrn.1666141> [hereinafter Karapanou & Visscher, *Way Out of the Impasse*].

<sup>85</sup> Visscher, *Time is Money?*, *supra* note 77. The paper reached to an average amount of 2.50 Euros per hour. For an application of QALY to Dutch tort law specifically within the same stream of literature, see Louis Visscher, *QALY-tijd in de vaststelling van smartengeld bij letsel?*, 4 TIJDSCHR. VOOR VERGOED. PERS. 93 (2013) (Neth.).

<sup>86</sup> Visscher, *Time is Money?*, *supra* note 77; Karapanou & Visscher, *Better Assessment of Damages*, *supra* note 82.

<sup>87</sup> Karapanou & Visscher, *Magnitude of Pain*, *supra* note 79; Karapanou & Visscher, *Better Assessment of Damages*, *supra* note 82, at 49.

literature, fall within these fields where quantification of immaterial is necessary for accuracy.<sup>88</sup>

Comparing QALY values gives an estimation of the relative values of different possible treatments for the patient,<sup>89</sup> so the estimation should be as accurate as possible. For privacy in e-health, estimations are easier and more straightforward than they are in the context of tort law, as in the context of e-health they need not assume instrumental rationality.

The CEA literature, in which QALYs are traditionally embedded, was largely born out of a necessity to formally measure all costs and benefits of any particular treatment in the face of difficult policy decisions stemming from large healthcare costs and limited resources. When maximizing patients' well-being subject to a budgetary constraint, there was no reason to take into account solely the monetary costs and benefits of each possible treatment. Similarly, in the face of growing concerns about privacy and as new medical interventions appear that track and store sensitive patient information, there is no reason to ignore this dimension of patients' well-being.

Insofar as privacy is an important consideration for patients' well-being, it is sensible to impose some qualifier on e-health treatments by giving prevalence to those that avoid collecting large amounts of sensitive data or restrict such collection to the data that are strictly necessary for the treatment. This goal can be done formally through the CEA method described in the previous section.

With the suggested policy, the ICER values of treatments will reflect societal preferences more accurately. Imagine that there are two potential treatments, *A* and *B*, which are equal in terms of monetary costs and (standard) QALY improvement when compared to the current treatment. However, treatment *A* involves the collection of data on patients' medical history and its dissemination among a network of healthcare employees while treatment *B* does not. The current calculations of the ICER will give the impression that both treatments are identically beneficial. However, if patients prefer not to have their data collected, thereby preferring treatment *B* over treatment *A*, the treatments will not be equally beneficial. The calculation should be different because their wellbeing will be different under each treatment.

### *C. Advancing Policy Discussions*

Another advantage of the suggested policy is that, given that it would allow for more accurate measurements of privacy costs, it would help advance the broader

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<sup>88</sup> One should note that the tort law suggestions are made in the institutional context of European Tort Law, which has a much more limited recognition of pain and suffering damages than its American counterpart. The proposal of QALYs in tort law, therefore, means to expand the recognition of pain and suffering damages, not contract it as it probably would in American law.

For the Netherlands in particular, where this proposal was made, the EuroVaQ report of 2010 derived amounts of willingness to pay of between 34,000 and 43,000 Euros per QALY. For estimating non-pecuniary damages in this country, a value of 50,000 Euros per QALY has been suggested for corresponding with recent findings on willingness-to-pay within the country and for lying in the middle of the upper and lower boundaries of 20,000 and 80,000 Euros, which are often mentioned. See Visscher, *Time is Money?*, *supra* note 77.

<sup>89</sup> Karapanou & Visscher, *Better Assessment of Damages*, *supra* note 82, at 59-63.

discussion surrounding privacy and e-health. So far, there is little indication of how important privacy really is to patients and how important it should be for doctors and policymakers, especially in the face of possible health gains. Including privacy concerns in CEA through QALYs would give a concrete measure of its importance.

Two major healthcare failures illustrate the usefulness of advancing the privacy discussion in this direction and the tensions that would be resolved.<sup>90</sup> In the United Kingdom, an initiative of the National Health Service created a database of harmonized patient records named *care.data* with the idea that insurance and drug companies could purchase statistical health data from the database.<sup>91</sup> The initiative, however, was halted after complaints from both patients and doctors.<sup>92</sup> Patients and doctors specifically raised complaints about the right to object to the collection of data under European Data Protection Law,<sup>93</sup> how the information would be used and stored securely, and the burden on doctors.<sup>94</sup> The rollout of the scheme has been postponed at the time of writing this article in order to “listen and act on the views of patients, the public, GPs and stakeholders, and to explain the benefits and risks involved,”<sup>95</sup> and it will likely be cancelled in the near future.

The Netherlands put forth a proposal similar to the United Kingdom’s scheme through the *Elektronisch Patiëntendossier (Electronic Patients’ File)*. The *Electronic Patients’ File* proposed to assemble the different pieces of information that doctors and healthcare providers possessed for each patient across the country.<sup>96</sup> A unified database would facilitate information sharing among different medical professionals and other healthcare providers to improve the quality, safety, and efficiency of healthcare for Dutch patients.<sup>97</sup> However, this initiative was also stopped due to

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<sup>90</sup> These do not pertain remote patient monitoring, which has been used as an example of e-health so far, but they pertain the administration of electronic health records. These also affect patients’ privacy, although while remote patient monitoring mainly (although not exclusively) impacts privacy at the stage of collecting personal information, electronic health records do so at the storage stage.

<sup>91</sup> Randeep Ramesh, *NHS Patient Data to Be Made Available for Sale to Drug and Insurance Firms*, THE GUARDIAN (Jan. 19, 2014), <https://www.theguardian.com/society/2014/jan/19/nhs-patient-data-available-companies-buy>.

<sup>92</sup> Sarah Boseley, *NHS to Scrap Single Database of Patients’ Medical Details*, THE GUARDIAN (July 6, 2016), <https://www.theguardian.com/technology/2016/jul/06/nhs-to-scrap-single-database-of-patients-medical-details>.

<sup>93</sup> Council Directive 95/46, art. 14, 1995 O.J. (L 281) (EC).

<sup>94</sup> See Ian Sample, *Public Should Be Consulted on NHS Medical Data-Sharing Scheme*, THE GUARDIAN (Feb. 2, 2015), <https://www.theguardian.com/society/2015/feb/03/medical-data-sharing-scheme-nuffield>; Ramesh, *supra* note 91.

<sup>95</sup> *The care.data programme*, NATIONAL HEALTH SERVICE OF ENGLAND (Aug. 31, 2016), <https://www.england.nhs.uk/ourwork/tsd/care-data/>; Letter from Tim Kelsey, Nat’l Dir. For Patients and Info., Nat’l Health Serv. of England., to his colleagues (Apr. 14, 2014), <https://www.england.nhs.uk/wp-content/uploads/2014/04/cd-stakeholder-lett.pdf>.

<sup>96</sup> Marieke Zwaanswijk et al., *Benefits and Problems of Electronic Information Exchange as Perceived by Health Care Professionals: An Interview Study*, 11 BMC HEALTH SERVS. RES. no. 256 1 (2011).

<sup>97</sup> Basit Chaudhry et al., *Systematic Review: Impact of Health Information Technology on Quality, Efficiency, and Costs of Medical Care*, 144 ANNALS INTERNAL MED. 742, 748 (2006).

privacy concerns.<sup>98</sup> In particular, the public was concerned with the broad scope of people that would have access to the data and the enhanced risks of having such large amounts of sensitive information in one single database, given the possibility of personal data being leaked.<sup>99</sup>

The rollout of both *care.data* and the *Electronic Patients' File* failed because the general public became wary about the access and security of their personal data, probably legitimately so.<sup>100</sup> The creators of the policies did not sufficiently take into account privacy considerations when creating or developing these policies. In failing to consider privacy concerns, the policies resulted in significant amounts of efforts and money going to waste.

The creators of the policies might have cared about privacy, and they most surely cared about their policies' long-term success, but they did not have a tool to accurately estimate the weight that they should have given to privacy concerns.<sup>101</sup> Different versions of both of these policies, incorporating privacy concerns, could have withstood public scrutiny. As these examples illustrate, this article's proposal would not only benefit patients, but would also protect policies from failure after the government has already invested significant money and resources. Even if the method turned to be inaccurate as a tool for predicting constituents' privacy concerns, it could show that privacy concerns were seriously taken into account, therefore eliminating the discussion's dichotomy and providing a common ground for deliberation.

#### D. Doctrinal Implications

While exploring in detail the legal framework of privacy in health is beyond the scope of this article, mapping how its underlying principles can be better achieved by the proposal made here can be useful to understand the normative implications of the policies just described.

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<sup>98</sup> The legislative power rejected the initiative unanimously. After that, 44 regional databases were set up under an opt-in basis. *Eerste Kamer verwerpt patiëntendossier [Senate Rejects Patient File]*, NU.NL (Apr. 5, 2011) (Neth.) [hereinafter *Senate Rejects Patient File*], <http://www.nu.nl/politiek/2484753/eerste-kamer-verwerpt-patientendossier.html>. After that, 44 regional databases were set up under an opt-in basis. *Lot LSP in handen van zorgverleners [LSP Fate in the Hands of Health Care Providers]*, PHARMACEUTISCH WEEKBLAD [PHARMACEUTICAL WEEKLY] (Sept. 27, 2011) (Neth.), <http://www.pw.nl/nieuws/2011/lot-lsp-in-handen-van-zorgverleners>.

<sup>99</sup> *Wetsvoorstel EPD verworpen en overig nieuws [SPD Rejected Bill and Other News]*, EERSTE KAMER DER STATEN-GENERAAL [SENATE OF THE STATES GENERAL] (Aug. 31, 2016) (Neth.), [https://www.eerstekamer.nl/nieuws/20110405/wetsvoorstel\\_epd\\_verworpen\\_en](https://www.eerstekamer.nl/nieuws/20110405/wetsvoorstel_epd_verworpen_en;); *Senate Rejects Patient File*, *supra* note 98.

<sup>100</sup> *Senate Rejects Patient File*, *supra* note 98.

<sup>101</sup> So far we have worked with situations in which a health insurance or a national health service covers treatments. It is not entirely clear what would happen when a treatment crosses jurisdictional boundaries with different privacy governance regimes and there is no clear applicable law. See Bonnie Kaplan & Sergio Litewka, *Ethical Challenges of Telemedicine and Telehealth*, 17(4) CAMBRIDGE Q. HEALTHCARE ETHICS 401, 401 (2008). For cases between the U.S. and the E.U., this situation could be addressed by referring to the Privacy Shield. See U.S. DEP'T OF COMMERCE, E.U.-U.S. PRIVACY SHIELD FRAMEWORK, <https://www.privacyshield.gov/EU-US-Framework> (last visited Nov. 12, 2016).

The law recognizes already the importance of privacy specifically for medical data. Health data are riskier and more sensitive than other kinds of personal data, and their special legal protection reflects this increased importance and sensitivity.<sup>102</sup> In the U.S., patients' health data are protected by various specific regulations that capture the increased sensitivity of medical data when compared to other kinds of personal data and grant medical data enhanced protection, the most important of these being the Health Insurance Portability and Accountability Act (HIPAA).<sup>103</sup> But HIPAA covers only the privacy and security of clinical data (not commercial data) that are managed by a healthcare organization. E-Health devices that do not fit into this category fall into standard consumer protection and contract law. According to the Federal Trade Commission, these privacy claims would need a contractual basis.<sup>104</sup>

Similarly, in the E.U. Data Protection Framework, the idea of the increased sensitivity of medical data is captured in the provisions of the Data Protection Directive regarding health data, but in a much broader way.<sup>105</sup> In line with its increased sensitivity, the current Directive and the coming GDPR establish health data as a special category, requiring a higher level of protection in the form of consent for such data collection or processing.<sup>106</sup>

The proposal made here advances the aims of these legal frameworks in two ways. The first relates to consent. The second relates to common fair information practice principles.

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<sup>102</sup> See Bonnie Kaplan, *Patient Health Data Privacy*, in SHLOMIT YANISKY-RAVID, *BEYOND IP: THE FUTURE OF PRIVACY* (Fordham U. Press, forthcoming 2017).

<sup>103</sup> Health Insurance Portability and Accountability Act of 1996, 42 U.S.C. §§ 242k, 1320d (2016). Most relevant are the Administrative Simplification rules: the Privacy rule, the Transactions and Code Sets rule, the Security rule, the Unique Identifiers rule, and the Enforcement rule. See Health Insurance Portability and Accountability Act §§ 261-64; 45 C.F.R. §§ 160, 164(A), 164(E) (2016) (privacy rule); 45 C.F.R. § 162(J) (2016) (transactions and code sets rule); 45 C.F.R. §§ 160, 164(A), 164(C) (2016) (security rule); 45 C.F.R. § 162(D) (2016) (unique identifiers rule); 45 C.F.R. §§ 160(C)-(E) (2016) (HIPAA enforcement rule).

<sup>104</sup> "Acne Cure" Mobile App Marketers Will Drop Baseless Claims Under FTC Settlements, FTC (Sept. 8, 2011), <https://www.ftc.gov/news-events/press-releases/2011/09/acne-cure-mobile-app-marketers-will-drop-baseless-claims-under>. The data privacy provision of the Communications Act is also applicable to the transfer of health data. See Anne Marie Helm & Daniel Georgatos, *Privacy and mHealth: How Mobile Health "Apps" Fit into a Privacy Framework Not Limited to HIPAA*, 64 SYRACUSE L. REV. 131, 148-58 (2014) (arguing the extent to which the presence of health information in mHealth does not limit the privacy law analysis to HIPAA).

<sup>105</sup> Council Directive 95/46, art. 6, 1995 O.J. (L 281) (EC). Unlike in the U.S., in the E.U., health data is defined as any data that relate to health. The General Data Protection Regulation (GDPR), which will replace the Directive in May 25, 2018, follows the Directive on this issue.

<sup>106</sup> Council Directive 95/46, art. 8(1), 1995 O.J. (L 281) (EC); Council Directive 95/46, recitals 33-34, 1995 O.J. (L 281) (EC). In order to ensure an adequate level of health protection, the directive also limits the applicability of special categories of data when data processing is necessary for the provision of health care or the management of healthcare services. See Council Directive 95/46, art. 8(3), 1995 O.J. (L 281) (EC).



In both of the jurisdictions described, the key aspect of health data's special protection when compared to other forms of data revolves around the increased importance of consent.<sup>107</sup> Although regulations differ from one jurisdiction to another, the patient's consent is necessary to transfer medical data to a third party in all jurisdictions.<sup>108</sup> The role that the consent requirement plays in determining medical treatments is addressing the need to ensure that patients are informed of all aspects of the technology, including the privacy aspect.

It is impossible for healthcare providers to inform patients of treatments' privacy consequences if they ignore these consequences themselves. Thus, the method proposed here is a useful exercise not only for health policy to determine the best medical treatments under all dimensions, but also to pull doctor-patient relations closer to HIPAA standards. By making privacy costs salient to healthcare providers, it enables them to communicate all implications of medical treatments to patients and makes a step forward towards patients' consent.<sup>109</sup>

The proposal is also supported by a substantive interpretation of widespread fair information practice principles—in particular, the collection limitation principle and the purpose specification principle. The collection limitation principle, besides mandating that information collection be limited and performed through lawful and fair means, suggests that it must be minimal for the purpose to which the collection takes place,<sup>110</sup> an idea that is also reflected in HIPAA's minimum necessary standard.<sup>111</sup> The purpose specification principle and, indirectly, the data quality principle, establish that the collection of data must be relevant for the purpose of the collection.<sup>112</sup>

A health policy that approves medical treatments without measuring each treatment's impact on privacy will often—if not always—breach these principles, as it will be blind to data collection and processing. Currently, it is difficult—if not

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<sup>107</sup> Melissa M. Goldstein, *Health Information Technology and the Idea of Informed Consent*, 38 J. L. MED. & ETHICS 27, 34 (2010); Kaplan & Litewka, *supra* note 101, at 406-07.

<sup>108</sup> TIMOTHY S. JOST, READINGS IN COMPARATIVE HEALTH LAW AND BIOETHICS (Carolina Academic Press, 2007); Kaplan, *supra* note 102. However, HIPAA mandates so “as appropriate.”

<sup>109</sup> Consent operates in two dimensions: consenting to the processing of one's personal data and consenting to a treatment. While these can be conflated in practice, they operate differently (for the second, HIPAA requires informed consent). Both would be enhanced by the policy proposed here.

<sup>110</sup> GUIDELINES ON THE PROTECTION OF PRIVACY AND TRANSBORDER FLOWS OF PERSONAL DATA, ORG. ECONOMIC CO-OPERATION AND DEV. (1980) [hereinafter GUIDELINES]; *see also* LINDA KOONTZ, INFORMATION PRIVACY IN THE EVOLVING HEALTHCARE ENVIRONMENT 7-10 (2013).

<sup>111</sup> *See* Health Insurance Portability and Accountability Act §§ 261–64; 45 C.F.R. §§ 160, 164(A), 164(E) (2016). *See also* U.S. DEP'T OF HEALTH & HUMAN SERVS., SUMMARY OF THE HIPAA PRIVACY RULE, <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/> (last visited Nov. 7, 2016) [hereinafter SUMMARY OF THE HIPAA PRIVACY RULE].

<sup>112</sup> GUIDELINES, *supra* note 110; *see also* KOONTZ, *supra* note 110. However, HIPAA allows for secondary use of information without consent when it is necessary for research, public health, law enforcement, judicial proceedings, or any other public interest activity. *See* SUMMARY OF THE HIPAA PRIVACY RULE, *supra* note 111.

impossible—to know whether a treatment (*A*) is necessary or proportionate compared to another less privacy invasive treatment (*B*). In the simplest case, where *A* and *B* achieve the same result, some account of their privacy aspects must take place to illustrate the superiority of *A* and avoid leaving a healthcare provider indifferent between them. In a more interesting case, where *A* provides a slightly better health benefit, but is significantly more privacy-invasive than *B*, a method of quantification like the one proposed here allows for comparison in accordance with these principles. This method could potentially show a disproportion such that we would not consider treatment *A* to be acceptable. Thus, these fair information practice principles would be better fulfilled with the method proposed here.

## VI. CONCLUSION

As medical treatments have become increasingly invasive and data intensive, concerns have been raised regarding the privacy of patients.<sup>113</sup> The discussion regarding privacy concerns has become increasingly important for both medical professionals and patients, resulting in some interventions being halted in order to assess the possibility of data breaches.<sup>114</sup>

This article proposes a method to formalize the discussion regarding privacy concerns by giving some indication of the value of personal information in a medical context and by including privacy in the overall costs and benefits of a given medical program. This article suggests this be accomplished by incorporating privacy concerns into the cost-effectiveness framework that is already established and in use in public health policy.

In order to incorporate privacy into the cost-effectiveness ratio, some kind of cost must be assigned to a decline in privacy. It was shown, however, that measuring the “price” of privacy through monetary costs is a difficult procedure that often results in paradoxical and inconsistent results, especially when the trade-off is presented in the typical context of purchase history information.

If monetization of privacy harms is to be attempted, I suggest, as a second best option, similar trade-off experiments where the data being collected are instead presented as sensitive health information. Experimental settings should be wary of the variable value of different types of information and the effects of privacy risk awareness. Therefore, this method would give more accurate results.

To more adequately measure privacy concerns, the current approach should shift to incorporate a method whereby the cost of privacy is embedded in the measurements of health states. Using the Visual Analogue Scale, Standard Gamble, and Time-Trade-Off methods with minor alterations yields utility measurements of a given health state, as well as a given level of privacy invasion. These methods can be extended to measure utility under different categories of information and probabilities of data breach. In this framework, the costs and benefits of a treatment are explicitly measured, and treatments with a high amount of data collection and a higher probability of making sensitive data public are given a concrete penalty, which allows for an objective comparison between potential medical interventions.

If the proposed policy suggestion were to be followed in a few e-health treatments, its results could be tested against existing economic evaluations of different health treatments (QALY and ICER) in order to compare the outcomes of

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<sup>113</sup> *Id.*

<sup>114</sup> *Id.*; see Boseley, *supra* note 92.

the standard evaluations with those of the proposed application. The expected outcome of this test is that e-health treatments involving any kind of patient surveillance—and in particular, remote patient monitoring—will rank lower than in standard tests, accounting for the introduced privacy violations. It is uncertain, however, how much lower they will rank, and it will remain so until these evaluations are performed.<sup>115</sup> Even when incorporating privacy elements, medical treatments would retain some, if not most, of their usefulness.

Either way, such tests would push forward the discussion of privacy in medicine by giving us an objective measure. It would indicate if and how much we should take privacy concerns in e-health into account.

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<sup>115</sup> Individuals may be more sensitive to breaches of medical data, but they may also be more responsive to health benefits.