



## CRYONICS AND THE HIPAA PRIVACY RULE

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John Niman, in his passion for transhumanism and technology shares his research efforts toward healthcare privacies, such as the Health Insurance Portability and Accountability Act, and how they are applicable to members of cryonics facilities and/or those who are already cryopreserved.

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Broadly construed, cryonics is the process of preserving a legally dead human being or animal at very low temperatures [Alcor].<sup>1</sup> Most often people who undergo cryonics suffer from currently untreatable or unsuccessfully treated diseases (like cancer) or old age and hope to be resuscitated at some indeterminate point in the future when both the technical difficulties of “thawing” a preserved human can be overcome and their disease can be cured [Alcor 2012].<sup>2</sup> Approximately 200 people have undergone cryonic suspension, though the procedure is becoming more popular, particularly in futurist and transhumanist circles [Best 2012].<sup>3</sup> Within the United States, only people who are already legally dead can be cryopreserved, even though this increases the likelihood of cellular damage [Alcor 2012].<sup>4</sup> This is because cryopreserving people who are alive “kills” them (presumably because no one has recovered from the cryopreservation process yet, and certainly not routinely) and, thus, a cryonics employee who cryopreserves a patient when that patient is still alive has murdered the patient. Still, because legal death occurs when the heart stops beating, as opposed to the cessation of brain activity, a patient who dies near the cryonics center has a better chance of being preserved with minimal cellular damage [Alcor 2012].<sup>5</sup> Even though all cryonics patients are legally dead, according to

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<sup>1</sup> Alcor. [2012] *What is Cryonics?* Retrieved May 7, 2012 <http://www.alcor.org/AboutCryonics/index.html>

<sup>2</sup> Id.

<sup>3</sup> Best, Ben. [2012] *Cryonics – Frequently Asked Questions. (FAQ)* Retrieved May 7, 2012 [http://www.benbest.com/cryonics/CryoFAQ.html#\\_VP\\_](http://www.benbest.com/cryonics/CryoFAQ.html#_VP_)

<sup>4</sup> Alcor. [2012] *Frequently Asked Questions.* Retrieved May 7, 2012 <http://www.alcor.org/FAQs/faq01.html#dead>

<sup>5</sup> Alcor. [2012] *Frequently Asked Questions.* Retrieved May 7, 2012 <http://www.alcor.org/FAQs/faq01.html#begin>

the website of Cryonics Institute, a leading cryonics facility, “[c]ryonics is regarded as an experimental medical treatment...” [Cryonics Institute 2012].<sup>6</sup> Thus, those who perform cryonics procedures seem to view the cryonics process as an extended lull in life, like a long gap before restarting a patient’s heart, as opposed to an end-of-life procedure that might eventually bring the patient “back” from the dead.

Congress passed the Health Insurance Portability and Accountability Act (HIPAA) in 1996, and the Privacy Rule followed in 2000 [U.S. Dept. of Health and Human Services 1996].<sup>7</sup> The Privacy Rule was revised in 2002 [id 2002]<sup>8</sup> and Congress is considering further modifications currently as part of the Health Information Technology for Economic and Clinical Health [HITECH] Act.<sup>9</sup> The purpose of the HIPAA Privacy Rule is to regulate the use and disclosure of Protected Health Information (PHI) by certain Covered Entities, defined to include Health Plans, Health Care Clearinghouses, and those Health Care Providers who transmit health information in electronic form in connection with certain standard transactions.<sup>10</sup> The HITECH Act proposes extending the requirements of the HIPAA Privacy Rule to a fourth category of persons and institutions; Business Associates and altering the rules regarding disclosure of Protected Health Information after death.<sup>11</sup>

The first issue explored in this paper is whether cryonics facilities are either Covered Entities or Business Associates as defined by the HIPAA Privacy Rule. I will additionally explore the policy implications of either including cryonics facilities in, or excluding them from, the class of entities regulated by the HIPAA Privacy Rule.<sup>12</sup> I conclude by determining that the HIPAA Privacy Rule does not currently cover cryonics facilities because cryonics facilities are neither engaged in standard transactions nor are Business Associates with a Covered Entity, but I argue that cryonics facilities ought to be covered under the HIPAA Privacy Rule when it is next revised, and the proposed disclosure of PHI fifty years after the death of a patient needs to be revised for cryonics patients.

### **Health Care Clearinghouses:**

Health Care Clearinghouses are public or private companies that either process nonstandard information received from another entity into standard form or receives a standard transaction from another entity and processes the information into nonstandard form.<sup>13</sup> According to the definition, these include billing companies, re-pricing companies, community health information management systems, and “value-added networks and switches if these entities perform clearinghouse functions.”<sup>14</sup> Because cryonics facilities do not perform any of these functions,

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<sup>6</sup> Cryonics Institute. [2012] *New Horizons in 21<sup>st</sup> Century Life Extension: About Cryonics?* Retrieved May 7, 2012 <http://www.cryonics.org/reprise.html>

<sup>7</sup> U.S. Dept. of Health and Human Services [1996] *HIPAA Privacy Rule*. Retrieved May 7, 2012 <http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/index.html>

<sup>8</sup> Id.

<sup>9</sup> U.S. Dept. of Health and Human Services [n.d.] Notice of Proposed Rulemaking to Implement HITECH Act Modifications. Retrieved May 7, 2012

<http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/hitechprm.html>

<sup>10</sup> *Supra*, note 7

<sup>11</sup> Id.

<sup>12</sup> Id.

<sup>13</sup> Id.

<sup>14</sup> Id.

they are certainly not Health Care Clearinghouses and, thus, not subject to the HIPAA Privacy Rule under this provision.

### **Health Plans:**

Health Plans are what most people would consider insurance companies; HMOs, Medicare, Medicaid, supplement insurers, employer-sponsored health insurance plans, government health plans, etc.<sup>15</sup> Although cryonics facilities are generally paid from life insurance policies [Cryonics Institute 2012]<sup>16</sup> because cryonics facilities themselves are not health insurance companies, they are not covered entities under this provision either. Although Health Care Providers are the third type of entity currently covered by the HIPAA Privacy Rule, deciding whether or not a cryonics facility is a Health Care Provider is a much more complicated question. As such, I will quickly show why cryonics facilities are not Business Associates, and thus would not be covered under the modifications as proposed in accordance with the HITECH Act, before exploring the Health Care Provider question.

### **Business Associates:**

Business Associates are people or businesses that perform certain activities on behalf of Covered Entities involving the use of individually identifiable health information.<sup>17</sup> Examples of the covered activities include claims processing, data analysis, utilization review, billing, legal, actuarial, accounting, consulting, data aggregation, managerial, administrative, accreditation, or financial services.<sup>18</sup> Because cryonics facilities are businesses unto themselves, and do not perform services on behalf of Covered Entities (roughly, hospitals and other health care providers) they are not considered Business Associates under the proposed regulations. Even if cryonics facilities were to provide their services on behalf of a Covered Entity, the type of service they provide (maintenance or storage of patients preserved at very low temperatures), likely does not fall within the enumerated categories of the definition of Business Associates and so cryonics facilities still would not be covered under the Business Associate provision of the HIPAA Privacy Rule. Having eliminated three of the four possible categories of Business Associates, only the more difficult question of whether cryonics facilities are Health Care Providers remains.

### **Health Care Providers:**

Under the HIPAA Privacy Rule, Health Care Providers means any “provider of service[s]” like a hospital, and “providers of medical or health services” (doctors, dentists, etc.) as defined by Medicare and anyone else who furnishes, bills, or is paid for healthcare.<sup>19</sup> Even if a cryonics facility generally does not interact with a patient until they are dead and delivered to the facility, on at least some occasions doctors at the facility assist the patient before death so that they can

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<sup>15</sup> Id.

<sup>16</sup> Cryonics Institute. [2012] *New Horizons in 21<sup>st</sup> Century Life Extension: About Cryonics?* Retrieved May 7, 2012 <http://www.cryonics.org/reprise.html> (“A Lifetime Member pays a one-time fee ... usually by making CI the beneficiary of a life insurance policy.”)

<sup>17</sup> Supra, note 7

<sup>18</sup> Id.

<sup>19</sup> Id.

begin the preservation procedures as quickly as possible. Alcor seems to direct its patients to other, affiliated companies for these end-of-life services, but other companies may not.<sup>20</sup> Even assuming all cryonics facilities work as Alcor does, however, patients expect to be revived eventually, and the cost of revival is (theoretically) included in the fee paid to the cryonics facility (plus the interest that fee earns in the meantime.)<sup>21</sup> The staffs of cryonics facilities likewise seem to believe that they are maintaining patients who, if they are not currently alive, will again be alive at some point in the future. They view the process as, alternatively, maintaining a living person or storing a legally dead person for revival later. If what they are actually doing is maintaining a person who is alive, then it seems reasonable to assume that what the staffs of cryonics facilities are doing is essentially the same thing that doctors at hospitals do when they maintain patients who are in comas or persistent vegetative states. If, however, the cryonics facilities are engaged in the business of bringing people back from legal death, then the process of bringing a legally dead person back to life is considered medical care in a hospital, and still would likely be considered medical care in the cryonics context; the HIPAA Privacy Rule as it relates to Health Care Providers is very broad.

There is, however, a catch; only those Health Care Providers who engage in “transactions” are required to comply with the HIPAA Privacy Rule.<sup>22</sup> Transactions, in turn, mean transmitting in electronic form information related to health care claims, health care payment and remittance advice, coordination of benefits, health care claim status, enrollment or eligibility in a health care plan, referral certifications, first reports of an injury, health claim attachments and anything else the Secretary prescribes by regulations for the purposes of carrying out “financial or administrative” activities related to health care.<sup>23</sup> Cryonics providers, as best I can tell, are paid in one lump sum either from patients themselves or life insurance policies where the facility is named as the beneficiary. As such, it seems unlikely that the cryonics facilities would be engaged in these transactions and thusly, be required to comply with the HIPAA Privacy Rule.<sup>24</sup> To be sure cryonics facilities are not the only medical providers that avoid compliance with the HIPAA Privacy Rule in this way (and they probably provide less medical services than some of the other companies that avoid compliance), but for a cryonics patient concerned about the privacy of their PHI, this provision might be troubling.

As it stands, cryonics facilities are not covered by either the current HIPAA Privacy Rule or the Rule as potentially amended by the HITECH Act. Some states modify the HIPAA Act (including the Privacy Rule) to be more expansive (by eliminating the requirement that health care information be sent in conjunction with a standard transaction, for instance) and so, in those states, a cryonics facility might be covered under the state version of the HIPAA Privacy Rule if they are engaged in acts that the state perceives as medical care. ‘Check your local jurisdiction’, however, is standard advice and not particularly helpful to those who live in states that have adopted the default rule promulgated by Congress. The question then, is whether cryonics facilities ought to be covered by the HIPAA Privacy Rule as it exists or under the Privacy Rule as it stands to be amended by the HITECH Act. I argue that they should.

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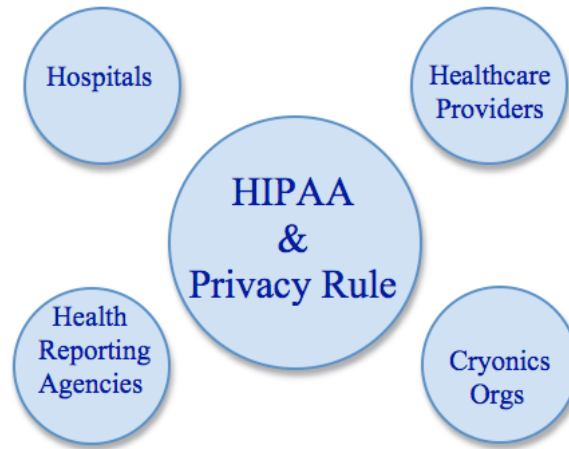
<sup>20</sup> <http://www.alcor.org/FAQs/faq06.html#conditions>

<sup>21</sup> <http://www.alcor.org/Library/pdfs/signup-CryopreservationAgreement.pdf> Pg. 7 at 7(f).

<sup>22</sup> 45 C.F.R. §160.102(a)(3)

<sup>23</sup> *Id.* §160.103 (definition of Transaction)

<sup>24</sup> *See Generally*: <http://www.alcor.org/BecomeMember/sdfunding.htm> and <http://www.cryonics.org/become.html>



### **The Scope Of Protection:**

If the HIPAA Privacy Rule did cover cryonics facilities, in what ways would cryonics facilities be restricted from using or disclosing information? Four portions of the statute deal explicitly with this. Within the U.S. Code of Federal Regulations, 45 C.F.R. §164.506 governs uses and disclosures of PHI for the purposes of treatment, payment, and health care operations.<sup>25</sup> 45 C.F.R. §164.508 governs uses and disclosures for which authorization from the patient is required.<sup>26</sup> 45 C.F.R. §164.510 covers situations in which the patient may object to a use or disclosure, but in which the Covered Entity is able to otherwise use or disclose the information if the patient does not object.<sup>27</sup> Finally, 45 C.F.R. §164.512 regulates the uses and disclosures for which neither an authorization nor an opportunity to object is required.<sup>28</sup> I will analyze each section in turn.

The treatment, payment, and operations exceptions governed by 45 C.F.R. §164.506 are extensive. The first couple of sections simply state that a Covered Entity may use information for these purposes as described in sub-section (c) unless an authorization is required under 45 C.F.R. §164.508 (a)(2) or (3) (for psychotherapy notes or marketing.)<sup>29</sup> The Covered Entity may (but is not required to) ask the patient to sign a consent form for any uses or disclosures under this section, but such a consent form will not replace an authorization form when an authorization form is required.<sup>30</sup> 45 C.F.R. §164.506(c)(1) states that a Covered Entity may use PHI for its' own treatment, payment, or health care operations.<sup>31</sup> 45 C.F.R. §164.506(c)(2) allows a Covered Entity to disclose information to another Health Care Provider for the purposes of treatment; for instance, one hospital might transfer a patient's file to another hospital when the patient moves to another state and starts going to a new doctor.<sup>32</sup> 45 C.F.R. §164.506(c)(3) allows a Covered Entity to disclose PHI to another Covered Entity or Health Care Provider for the *recipient's*

<sup>25</sup> 45 C.F.R. §164.506.

<sup>26</sup> Id. §164.508.

<sup>27</sup> Id. §164.510.

<sup>28</sup> Id. §164.512.

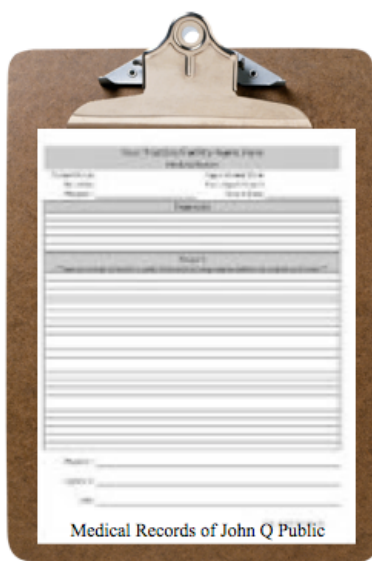
<sup>29</sup> Id. §164.506(a).

<sup>30</sup> Id. §164.506(b).

<sup>31</sup> Id. §164.506(c)(1).

<sup>32</sup> Id. §164.506(c)(2).

payment activities.<sup>33</sup> 45 C.F.R. §164.506(c)(4) allows a Covered Entity to disclose PHI to another Covered Entity for the *recipient's* health care operations activities provided that particular conditions are met.<sup>34</sup> Both entities need to have or have had some relationship with the individual whose PHI is being disclosed, the PHI must pertain to that relationship, and either is for a purpose mentioned in paragraph one or two of “health care operations<sup>35</sup>” or for the purpose of healthcare fraud and abuse detection or compliance.<sup>36</sup> Finally, 45 C.F.R. §164.506(5) allows entities that are part of a “health care arrangement” to disclose information to each other for any health care operations activities.<sup>37</sup>



While the uses and disclosures described in 45 C.F.R. §164.506 do not need patient authorization, the uses and disclosures in 45 C.F.R. §164.508 do require authorization forms.<sup>38</sup> 45 C.F.R. §164.508(2) requires authorization for psychotherapy notes.<sup>39</sup> Because cryonics facilities are unlikely to have or create psychotherapy notes, I will not detail the various exceptions and conditions. 45 C.F.R. §164.508(3) requires authorization for marketing – an activity much more relevant to cryonics facilities.<sup>40</sup> A Covered Entity is required to gain an

<sup>33</sup> Id. §164.506(c)(3).

<sup>34</sup> Id. §164.506(c)(4).

<sup>35</sup> Id. §164.506(c)(4)(i). The relevant paragraphs from “health care operations” read: (1) Conducting quality assessment and improvement activities, including outcomes evaluation and development of clinical guidelines, provided that the obtaining of generalizable knowledge is not the primary purpose of any studies resulting from such activities; population-based activities relating to improving health or reducing health care costs, protocol development, case management and care coordination, contacting of Health Care Providers and patients with information about treatment alternatives; and related functions that do not include treatment; (2) Reviewing the competence or qualifications of health care professionals, evaluating practitioner and provider performance, health plan performance, conducting training programs in which students, trainees, or practitioners in areas of health care learn under supervision to practice or improve their skills as Health Care Providers, training of non-health care professionals, accreditation, certification, licensing, or credentialing activities. Id. §164.501.

<sup>36</sup> Id. §164.506(c)(4)(ii).

<sup>37</sup> Id. §164.506(c)(5).

<sup>38</sup> Id. §164.508(a)(1).

<sup>39</sup> Id. §164.508(2).

<sup>40</sup> Id. §164.508(3).

authorization for all marketing that is not (1) face-to-face communication from a Covered Entity to an individual<sup>41</sup> or (2) a communication that takes the form of a gift of nominal value provided by the Covered Entity.<sup>42</sup> If the Covered Entity receives direct or indirect remuneration from a third party, then the Covered Entity must disclose that fact.<sup>43</sup> 45 C.F.R. §164.508(3)(i)(b) and its' associated subparts detail the sort of information that a proper authorization must contain,<sup>44</sup> the set of defects that will render an authorization ineffective,<sup>45</sup> the sorts of documents an authorization may be combined with,<sup>46</sup> when a Covered Entity may condition treatment and similar services to a patient on the patient's granting of an authorization,<sup>47</sup> how an individual may revoke an authorization,<sup>48</sup> and documentation requirements associated with authorizations.<sup>49</sup> Finally, 45 C.F.R. §164.508(3)(i)(c) and its subparts detail more of the specific details that must be included in authorizations.<sup>50</sup> In short, a cryonics facility could use some PHI under some circumstances for marketing purposes if it obtained a valid authorization from each individual whose PHI it wanted to use and the cryonics facility disclosed any information that it is required to disclose.

45 C.F.R. §164.510 strikes a sort of middle ground between the previous two sections. On one hand, an authorization is not required; on the other hand, the individual whose PHI is being disclosed must be notified in advance and have an opportunity to opt-out or restrict the disclosure.<sup>51</sup> This notice and acceptance, rejection, or restriction may be orally communicated.<sup>52</sup> 45 C.F.R. §164.510(a) allows Covered Entities to use some PHI to create a directory of individuals within its' facility and to disclose that information to either clergy or anyone else who asks about the patient by name.<sup>53</sup> 45 C.F.R. §164.510(b) regulates disclosures to family, friends, or other person identified by the individual information relating to the individual's care or payment.<sup>54</sup> The upshot of both sections is that Covered Entities may disclose some information to some people with just a verbal acknowledgment from the individual whose PHI is being disclosed so long as that individual is told ahead of time and has the opportunity to object or limit the disclosures. In some circumstances when the individual whose PHI is being disclosed is unable to accept, reject, or limit the disclosure due to injury or another reason, the Covered Entity may disclose information based on its "best judgment" and then notify the individual of the disclosure at the earliest possible opportunity.<sup>55</sup>

Finally, 45 C.F.R. §164.512 covers non-treatment, non-payment, and non-healthcare operations activities that require neither an authorization nor a disclosure.<sup>56</sup> There are twelve enumerated possibilities for such disclosures, and a host of rules about what information may be

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<sup>41</sup> Id. §164.508(3)(i)(A).

<sup>42</sup> Id. §164.508(3)(i)(B).

<sup>43</sup> Id. §164.508(3)(ii).

<sup>44</sup> Id. §164.508(3)(i)(b)(1).

<sup>45</sup> Id. §164.508(3)(i)(b)(2).

<sup>46</sup> Id. §164.508(3)(i)(b)(3).

<sup>47</sup> Id. §164.508(3)(i)(b)(4).

<sup>48</sup> Id. §164.508(3)(i)(b)(5).

<sup>49</sup> Id. §164.508(3)(i)(b)(6).

<sup>50</sup> Id. §164.508(3)(i)(c).

<sup>51</sup> Id. §164.510.

<sup>52</sup> Id.

<sup>53</sup> Id. §164.510(a).

<sup>54</sup> Id. §164.510(b).

<sup>55</sup> Id.

<sup>56</sup> Id. §164.512.

disclosed, to whom and under what circumstances. 45 C.F.R. §164.512(a) allows the entity to make disclosures that are required by law, though entities must follow the restrictions in subsections (c), (e), or (f).<sup>57</sup> 45 C.F.R. §164.512(b) allows Covered Entities to disclose PHI to a public health authority authorized by law to collect such information for the purpose of protecting the public from (1) disease, (2) or child abuse, (3) to the FDA (4) to anyone at risk of contracting a communicable disease if the Covered Entity or public health authority is authorized by other law to do so or (5) to an employer for the purposes of investigating workplace disease or injury.<sup>58</sup> Covered Entities are also allowed to disclose instances of domestic violence under particular circumstances,<sup>59</sup> for legal oversight purposes for particular purposes,<sup>60</sup> when ordered by a court of law or through other legal procedures,<sup>61</sup> when ordered by the police under some circumstances,<sup>62</sup> to inform the medical examiner, coroner, funeral director,<sup>63</sup> or organ procurement facility, about a decedent to the police for some purposes under some circumstances,<sup>64</sup> for some research purposes,<sup>65</sup> to prevent enumerated risks that endanger public safety,<sup>66</sup> when the government or military requests information,<sup>67</sup> or for workers compensation claims.<sup>68</sup>

Even if cryonics facilities were included within the definition of Covered Entities, few of these provisions would apply to activities in which they are likely to engage. Perhaps slightly more provisions would apply if the patient dies at the cryonics facility or if the patient does not have to ‘die’ before undergoing cryonics in the future and the cryonics facilities were able (and willing) to bill insurance for the services rendered to the patient while the patient was ‘alive.’ Individuals undergoing cryopreservation, for instance, are unlikely to (or need) to have their records transferred to another doctor, although they may be transferred to a different cryonics facility given the usual buying and merging of businesses. Cryonics facilities would be more regulated in the way that they are able to market their product, although I have not yet seen an advertisement for a cryonics facility that would violate the HIPAA Privacy Rule. Cryonics facilities might well create internal directories; the HIPAA Privacy Rule would regulate those directories if cryonics facilities were Covered Entities. The comparatively little regulation that the HIPAA Privacy Rule would impose upon cryonics facilities suggests that there is little compelling reason that they ought not to be covered (although I am sure that directors of cryonics facilities would disagree). There are however, positive reasons why cryonics facilities ought to be included within the definition of Covered Entities as well.

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<sup>57</sup> Id. §164.512(a).

<sup>58</sup> Id. §164.512(b)(i)-(v).

<sup>59</sup> Id. §164.512(c).

<sup>60</sup> Id. §164.512(d).

<sup>61</sup> Id. §164.512(e).

<sup>62</sup> Id. §164.512(f).

<sup>63</sup> Id. §164.512(g).

<sup>64</sup> Id. §164.512(h).

<sup>65</sup> Id. §164.512(i).

<sup>66</sup> Id. §164.512(j).

<sup>67</sup> Id. §164.512(k).

<sup>68</sup> Id. §164.512(l).





Cryo-containers (called dewars), at the Alcor Life Extension Foundation.  
Photo by L. Rhodes

### **The Purpose Of Cryonics:**

One reason the HIPAA Privacy Rule ought to regulate cryonics facilities is that those who undergo cryonic preservation generally consider cryonics a medical procedure. There are, admittedly, more standard medical facilities that are not Covered Entities under the HIPAA Privacy Rule. However, as those medical facilities are more standard, they are more likely to be more greatly regulated under the HIPAA Privacy Rule than cryonics facilities would be. Thus, the argument that the HIPAA Privacy Rule is too expensive to implement might be more applicable to those more standard medical facilities than to cryonics facilities. Additionally, patients stored in cryonics facilities undergo a more lengthy medical procedure than patients in comas or persistent vegetative states, and perhaps for periods much longer than they are. Conceivably, a cryonics patient could remain preserved for a hundred years or more. During that time, a great amount of medical information will be collected (although most of it will be quite mundane; temperature, heartbeat, perhaps other sensory readings that probably would not fluctuate very much). The sheer amount of medical information collected might be reason enough to include them within the HIPAA Privacy Rule.

Another reason cryonics facilities ought to be included within the HIPAA Privacy Rule is that patients undergoing cryonic preservation may have died from diseases they expect will not be disclosed to the public. As a patient must be declared legally dead before they undergo cryonics, it is probable that the patient's life officially ended at a Covered Entity before the body is transported to a cryonics facility. Wherever the patient dies, they elected cryopreservation with the expectation that when science is able to cure their condition, the cryonics facility or other doctors will revive and cure them. In order for a cryonics facility to know when they can revive a particular patient, they need to link the disease or condition that the person died from with that patient's identity. Extremely detailed medical information would likely help in the revival

process. Although some patients will die of ‘natural causes,’ strokes, heart attacks, and other problems that do not carry a social stigma, some patients may die of diseases like AIDS, Hepatitis, Syphilis, or Gonorrhea that do carry either a social stigma or lead to embarrassment for the individual if or when they are revived.

### **The Proposed Fifty Year Rule:**

Additionally, the basic idea of the HIPAA Privacy Rule is that PHI ought to be protected, whether or not it is embarrassing to any patient in particular. Initially, medical information was considered so private that it could not be disclosed even after the patient’s death in most cases. The HITECH Act proposes changing this policy to protect medical information for fifty years after death, but beyond that, the information may be disclosed without restriction. Presumably, Health and Human Services (“HHS”) feels that whatever the motivation behind protecting medical information during the life of the patient is, that fifty years after death either those motivations are not as strong or other motivations outweigh them.

The interesting question unique to cryonics patients is this: At what point are the patients considered dead? On one hand, the individual undergoing cryonic preservation must be declared ‘legally dead’ before the procedure begins – otherwise the cryonics facility killed the patient and has committed murder. This suggests that the fifty-year clock should begin running when they patient is declared dead, whether at a hospital or hospice facility. On the other hand, the patient elects cryopreservation because he or she expects to eventually be revived by the cryonics facility and live again. In the patient’s mind, they would not be ‘dead in the final sense that most people attribute to death, but are instead simply being stored and preserved for a period of time before they can be revived and restored to perfect health. This means that the ‘deceased’ patient believes themselves to be in something akin to a coma, and under the HIPAA Privacy Rule, whatever PHI is collected while a patient is in a coma is protected either until the patient is revived and cured or until fifty years after the patient’s death. Additionally, if a patient is revived (say seventy-five years in the future), then all the sensitive medical information that was collected, either before the patient underwent the cryopreservation procedure or while the patient was in a state of suspended animation, may be disclosed as a matter of public record. In this case, there seems to be no reason why HHS would feel that the medical information collected about a patient who is in a coma ought to be protected because it could potentially embarrass the patient once the patient woke up, while at the same time feeling that the medical information collected about a patient undergoing cryonic preservation ought not be protected because it would not be embarrassing for the patient once that patient woke up. The two sets of circumstances are largely the same, except that the comatose patient’s heart never stopped beating; a fact that hardly seems relevant when considering the reasons why PHI ought to be protected.

It seems plain to me that there is no rational reason why HHS would take one approach to patients in a coma and another to those in cryonics facilities. It is possible that HHS simply believes that patients cannot be revived from cryonic preservation and that there is, therefore, no need to protect the information of cryonics patients created while the patient is legally dead. It is possible that HHS is correct in believing that; to their credit, no one has ever been successfully revived. On the other hand, HHS is not in the business of protecting medical information for only those patients that are *likely* to need the protection. Certain terminal diseases that have never been cured can afflict patients, but if the proposed regulation takes effect, their medical information will remain protected for fifty years after they die. While HHS may believe that no

patient will ever be revived via cryonics, HHS cannot honestly claim that they *know* no patient will ever be reanimated after cryopreservation. Given that, it seems most reasonable to consider the pros and cons of either protecting or not protecting the health information of cryonics patients given either their eventual revival or their eventual, final death caused either by the attempted revival or because the technology to successfully revive a patient who has undergone cryopreservation never materializes.

### **The Effect Of Altering The HIPAA Privacy Rule and Disclosure Timeframe:**

I will assume first that HHS is right and no one is ever successfully revived from cryopreservation. Currently, cryonics facilities are not Covered Entities under the HIPAA Privacy Rule, and the patients are considered legally dead when they ‘die’ at the hospital or elsewhere. In a scenario where cryonics patients’ PHI is not protected for the duration of their suspended animation, the PHI may be disclosed fifty years after the initial ‘legal death’ of the patient and, because the patient is never successfully revived, they are never embarrassed or otherwise harmed by the disclosure (or, at least, not harmed in a manner different from any other deceased individual fifty years after death.) This seems like the rule is working as it does for all other individuals.

Where cryonics patients’ health information is protected throughout the duration of their suspended animation and is only allowed to be disclosed after the revival process fails, such that the patient can neither be revived nor placed again into suspended animation to try again later and the patient is never revived, the PHI of that patient is not allowed to be disclosed for some period of time beyond the original fifty-year window the HITECH Act suggests. Perhaps the cryonics patient is placed into suspended animation and the disease that they succumbed to is cured within a few years, but the reanimation process fails and the patient is irreversibly lost. In this case, only a few years of extra protection could be granted by the cryonics exception. However, it is possible that a cryonics patient could remain in a state of suspended animation for hundreds of years before anyone attempts to revive them, or perhaps the patient is never revived. In this case, the PHI of the cryonics patient could not be disclosed for a very long time, and potentially could never be disclosed so long as they remain in suspended animation.

As I mentioned at the beginning of the paper, approximately 200 people have already been placed into suspended animation. It seems unlikely that anyone would be seriously harmed if relatively few patients’ medical information were never disclosed. Even if tens or hundreds of thousands of individuals eventually underwent cryopreservation, it seems unlikely that more than a small percentage of people would be preserved in any given year unless the process is shown to work. Therefore, it is unlikely that anyone is harmed by the non-disclosure of PHI even if many more people are preserved through cryonics. Indeed, until and unless the HITECH Act changes the term of protection for PHI after death, HHS has already determined that no patient’s PHI may be disclosed *ever*. To have that rule still apply to a small subset of people seems to cause little or no harm. Therefore, in cases where cryonics patients are never revived, I conclude that it matters little whether HHS includes cryonics facilities within the definition of Covered Entity and requires that they abide by the HIPAA Privacy Rule or not.

Next, I will assume that some or all cryonics patients that undergo the procedure eventually are revived, whether within a few years after death or hundreds of years later. If HHS includes cryonics facilities within the definition of Covered Entities and the HIPAA Privacy Rule protects their patients’ PHI, then upon revival no information has been disclosed to the public and the

patient's privacy was respected. This is an ideal outcome given the belief that patient PHI ought to be protected.

If, however, cryonics facilities are not Covered Entities and these patients are eventually revived, if they are revived more than fifty years after their 'legal death,' then their PHI may have been disclosed. Whether or not this actually causes a problem (that is, if anyone in particular cares), HHS has determined that patient PHI is potentially embarrassing or is for other reasons worthy of protection. In this scenario, the HIPAA Privacy Rule has not protected these patients' PHI because cryonics facilities are not required to keep PHI private, and because hospitals, which otherwise are required to keep PHI private, are allowed to disclose the PHI fifty years after the patient supposedly 'died', but before they were revived. Whatever harm the HIPAA Privacy Rule is intended to prevent has occurred.

Given the relative harm that could occur from over-protecting patient PHI or under-protecting patient PHI, I conclude that it is more reasonable to require cryonics facilities to adhere to the HIPAA Privacy Rule for all PHI gathered while the patient is in a state of suspended animation, and for hospitals to maintain the confidentiality of patient PHI for more than fifty years while a cryonics patient is awaiting reanimation than it is for cryonics facilities to remain unregulated and to continue to allow hospitals to disclose patient PHI after 'legal death' but before the reanimation process has terminally failed. If cryonics facilities were willing to work together, or if Congress were willing to mandate such a thing, a directory of all patients preserved in cryonics facilities could provide an easy way for hospitals to check whether or not one of their former patient's PHI was allowed to be disclosed after their 'legal death.' This seems like a minimal burden to place, given the desire to protect patient PHI.

### **Conclusion:**

The HIPAA Privacy Rule does not currently regulate cryonics facilities. Because cryonics facilities do not engage in "standard transactions," they are not included within the definition of Covered Entity. However, the HIPAA Privacy Rule only regulates a few activities that cryonics facilities are likely to engage in, and so would not likely impose much of a burden upon cryonics facilities if they were required to comply with it. Additionally, because of the special nature of cryonics and the potentially same motivations that allow patient PHI to be disclosed fifty years after legal death do not apply to patients who are cryopreserved, the proposed disclosure rule ought to be altered to continue protecting a cryonics patient PHI throughout the patient's period of suspended animation. The harm that could possibly come from over protecting a cryonics patient PHI is far outweighed by the benefit to patients who are eventually revived from suspended animation and have not had their PHI publically disclosed.

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