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# Personal Health Records as a Tool for Transparency in Health Care (Draft)

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## Draft

# Personal Health Records as a Tool for Transparency in Health Care

Sharona Hoffman\*

This chapter explores the benefits and limitations of personal health records (PHRs) as a tool to promote transparency in health care. PHRs are electronic resources that enable patients to access and sometimes manage their health information, and they are often a component of physicians' electronic health record (EHR) systems.<sup>1</sup> Stage 2 of the meaningful use regulations for EHR systems establishes the following core objectives, among others: 1) "Provide patients the ability to view online, download and transmit their health information" and 2) "Use secure electronic messaging to communicate with patients on relevant health information."<sup>2</sup> PHRs are a key mechanism by which to achieve both goals.

While PHR use has lagged behind EHR system adoption, it is now becoming increasingly common. In 2014, twenty-two percent of patients viewed test results online, and in 2015, sixteen percent of physicians could exchange secure messages with patients as well as enable patients to electronically view, download, and transmit their medical records to third parties.<sup>3</sup> A much higher percentage had some but not all of these capabilities. Optimists forecast that by 2020, over 75% of health care providers will implement fully functioning PHRs.<sup>4</sup>

As PHR implementation accelerates, it is essential that all stakeholders understand their advantages and risks. Moreover, health care providers must develop thoughtful policies and regulations to address PHR concerns and promote their efficacy.

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<sup>1</sup> See *infra* Part I.

<sup>2</sup> Centers for Medicare and Medicaid Services (CMS), Stage 2 Overview Tipsheet (last updated August 2012), [https://www.cms.gov/regulations-and-guidance/legislation/ehrincentiveprograms/downloads/stage2overview\\_tipsheet.pdf](https://www.cms.gov/regulations-and-guidance/legislation/ehrincentiveprograms/downloads/stage2overview_tipsheet.pdf); 42 C.F.R. §495.22 (e)(8) & (9) (2016). The regulations include specific requirements as to how many patients must utilize these capabilities.

<sup>3</sup> The Office of the National Coordinator for Health Information Technology, Quick Stats, <https://dashboard.healthit.gov/quickstats/quickstats.php> (last visited December 29, 2016). See also, David P. Miller et al., *Primary Care Providers' Views of Patient Portals: Interview Study of Perceived Benefits and Consequences*, 18 no. 1 J. MED. INTERNET RES. e8 (2016), [https://www.jmir.org/article/viewFile/jmir\\_v18i1e8/2](https://www.jmir.org/article/viewFile/jmir_v18i1e8/2) (reporting that "only 10% of veterans had authenticated their patient portal account within the Veterans Health Administration system," that in large commercial health systems, typically less than 30-40% of patients activate their online access," and that in clinics serving primarily disadvantaged populations, portal use has been less than 10%.")

<sup>4</sup> Eric W. Ford et al., *Personal Health Record Use in the United States: Forecasting Future Adoption Levels*, 18, no. 3 J. MED. INTERNET RES. (2016), <http://www.jmir.org/2016/3/e73/>.

## I. What Are PHRs?

A PHR can be defined as “an electronic application through which individuals can access, manage and share their health information . . . in a private, secure, and confidential environment.”<sup>5</sup> There are two types of PHRs.

First, there are stand-alone PHRs consisting of software that enables patients to enter information from their medical records and to store it on their computer or the Internet. Patients may add data about their diet, exercise, or other matters that will help them track their progress and take better care of themselves. Some stand-alone PHRs can also accept entries from external sources such as laboratories, pharmacies, or insurers, and the patient can decide to share the PHR with loved ones or caregivers.<sup>6</sup> In the alternative, patients may opt for portable, interoperable stand-alone PHRs that are stored on smart cards, cellular phones, or USB-compatible devices.<sup>7</sup>

A second type of PHR is tethered to health care providers’ EHR systems. These PHRs, which are also called “patient portals,” are tied to the EHR system and are automatically populated with information from the EHR, including test results, clinical summaries, appointment schedules, problem lists, allergies, and more.<sup>8</sup> In some cases, Patients may also be allowed to enter information into the PHR, such as results of blood sugar tests, blood pressure checks, or other procedures that they conduct on their own at home.<sup>9</sup> Patients may also be able to order prescriptions through the PHR and exchange secure messages with clinicians.<sup>10</sup> This chapter focuses primarily on tethered PHRs.

## II. PHR Benefits

Studies in the United States and abroad show that patients are often enthusiastic about PHRs. PHRs hold significant promise for health care improvements and increased medical transparency.<sup>11</sup>

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<sup>5</sup> Paul C. Tang et al., *Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption*, 13 J. AM. MED. INFORM. ASSOC. 121, 122 (2006); see also Matthew Wynia & Kyle Dunn, *Dreams and Nightmares: Practical and Ethical Issues for Patients and Physicians Using Personal Health Records*, 38 J.L. MED. & ETHICS 64, 65 (2010) (offering a variety of other definitions).

<sup>6</sup> N. Archer et al., *Personal Health Records: A Scoping Review*, 18 J. AM. MED. INFORM. ASSOC. 515, 515 (2011); HealthIT.gov, *Are there different types of personal health records (PHRs)?* (last updated March 3, 2016), <https://www.healthit.gov/providers-professionals/faqs/are-there-different-types-personal-health-records-phrs>.

<sup>7</sup> Wynia & Dunn, *supra* note 5, at 65.

<sup>8</sup> Julie A. Dooling, *It’s about the Patient: Engagement through Personal Health Records and Patient Portals*, 14 No. 3 J. HEALTH CARE COMPLIANCE 33, 34 (2012); HealthIT.gov, *supra* note 6.

<sup>9</sup> Taya Irizarry et al., *Patient Portals and Patient Engagement: A State of the Science Review*, 17 J. MED. INTERNET RES. e148 (2015).

<sup>10</sup> Morgan J. Thompson et al., *Work System Barriers to Patient, Provider, and Caregiver Use of Personal Health Records: A Systematic Review*, 54 APPLIED ERGONOMICS 218, 219 (2016).

<sup>11</sup> Simon de Lusignan et al., *Patients’ Online Access to Their Electronic Health Records and Linked Online Services: A Systematic Interpretative Review*, 4 BMJ OPEN e006021 (2014), <http://bmjopen.bmj.com/content/4/9/e006021.full>; Kim M. Nazi et al., *Evaluating Patient Access to Electronic Health Records: Results from a Survey of Veterans*, 51 MED. CARE S52-S56 (2013).

## A. Greater Information Access and Better Health Outcomes

PHRs enhance medical transparency because they enable patients to access their data and help them feel more empowered in their relationships with health care providers. The HIPAA Privacy Rule has always mandated that patients have access to their health information, but it allows health care providers to take as long as thirty (or even sixty) days to respond to patient requests.<sup>12</sup> By contrast, PHRs furnish patients with real-time access to their data.

Rather than having to call medical offices for test results, patients can log onto their PHRs and easily view them. Those who cannot recall details from their office visit can look them up and find them in their record rather than remain confused or ignorant. Ideally, patients should also be able to transmit information to other clinicians or caregivers.<sup>13</sup>

All of these capabilities should increase patient satisfaction. They should also enable patients to obtain better care from their physicians and to be more active participants in their own care. Patients who can see their medication lists, test outcomes and further appointments on their PHRs may find it easier to adhere to their treatment plans. More extensive information should also help patients formulate questions for their physicians so that they better understand their conditions and therapies. In addition, patients can refer to their PHRs when communicating with other providers from whom they seek second opinions or specialized care and thus provide them with more accurate information.<sup>14</sup>

## B. Improved Communication

Secure messaging enables patients to communicate directly with their doctors without having to schedule an appointment or call the office receptionist.<sup>15</sup> While ordinary e-mail can easily be sent or copied to the wrong person, secure messaging is less vulnerable to privacy breaches.<sup>16</sup> Electronic communication can increase clinicians' accessibility and make patients feel that their doctors are responsive to them. Thus, online contact can enhance the clinician-patient relationship and improve patients' engagement, trust, and satisfaction.<sup>17</sup>

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<sup>12</sup> 45 C.F.R. §164.524(b)(2) (2016).

<sup>13</sup> Miller et al., *supra* note 3.

<sup>14</sup> *See Id.*

<sup>15</sup> Melissa Lester et al., *Personal Health Records: Beneficial or Burdensome for Patients and Healthcare Providers?*, 13 PERSPECT. HEALTH INF. MANAG. (Spring 2016), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4832132/pdf/phim0013-0001h.pdf>.

<sup>16</sup> Patricia R. Recupero, *E-mail and the Psychiatrist-Patient Relationship*, 33 J. AM. ACAD. PSYCHIATRY L. 465, 468 (2005) (explaining that "[t]he chance of misdirection and interception on ... [a] secure network is substantially less than in the case of e-mail accounts hosted by Internet service providers.").

<sup>17</sup> Yi Yvonne Zhou et al., *Patient Access to an Electronic Health Record with Secure Messaging: Impact on Primary Care Utilization*, 13 AM. J. MANAGED CARE 418, 424 (2007) (concluding that patients using electronic messaging had 6.7% to 9.7% fewer outpatient primary care visits than others); Kim M. Nazi, *The Personal Health Record Paradox: Health Care Professionals' Perspectives and the Information Ecology of Personal Health Record Systems in Organizational and Clinical Settings*, 15 J. MED. INTERNET RES. e70 (2013); J. Herman Blake et al., *The Patient-*

### C. Enhanced Efficiency

Patient portals may save medical offices time by reducing the volume of phone calls and requests for in-person appointments. First, patients who can look up their test results or request medication renewals electronically will not need to call their doctors' offices for these reasons. Second, staff can often prioritize and respond to secure messages much more quickly than they can answer or return phone calls. Finally, doctors who receive a detailed narrative from a patient regarding a question may be able to respond electronically without having to dedicate an office visit to the matter.<sup>18</sup>

### D. Increased Data Accuracy

Patients' medical records may become more complete and comprehensive with the help of PHRs. If patients add data about their diet, exercise, and medical monitoring activities (e.g. blood pressure or blood sugar checks), physicians will be able to gain a deeper understanding of patients' health status.

PHRs may also enable patients to detect errors in their medical records and to request that they be corrected. Patients who scrutinize their PHR data may notice that their medication lists, medical histories, problem descriptions, or other information is incorrect. The HIPAA Privacy Rule empowers individuals to request that their health information be amended and requires covered entities to comply with such requests when the information is in fact inaccurate or incomplete.<sup>19</sup> Although currently patients rarely initiate requests for amendment,<sup>20</sup> they could contribute an important layer of data quality control if they more regularly did so. Patient portals could make it easier for patients to request corrections and for clinicians to process these requests.<sup>21</sup>

PHRs may help elucidate the truth in the context of litigation as well. If patients communicate with physicians through secure messaging, there will be a complete record of the conversations' contents.<sup>22</sup> By contrast, phone calls generally are not recorded, and controversies regarding them may entail significant uncertainty and "he said, she said" assertions. Secure messaging, therefore, may be very useful for purposes of discovery.<sup>23</sup>

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*Surgeon Relationship in the Cyber Era: Communication and Information*, 22 THORATIC SURGERY CLINICS 531, 532-33 (2012).

<sup>18</sup> Miller et al., *supra* note 3.

<sup>19</sup> 45 C.F.R. § 164.526(a) (2016).

<sup>20</sup> David A Hanauer et al., *Patient-Initiated Electronic Health Record Amendment Requests*, 21 J. AM. MED. INFORM. ASSOC. 992, 992 (2014) (finding that "[a]mong all of the patients requesting a copy of their chart, only a very small percentage (approximately 0.2%) submitted an amendment request").

<sup>21</sup> Dooling, *supra* note 8 (noting that "in some organizations, this process is being accomplished using portal technology.").

<sup>22</sup> Miller et al., *supra* note 3.

<sup>23</sup> See SHARONA HOFFMAN, *ELECTRONIC HEALTH RECORDS AND MEDICAL BIG DATA: LAW AND POLICY* 95-96 (Cambridge University Press 2016) (discussing discovery).

### III. PHR Shortcomings

PHRs have not been greeted with uniform enthusiasm. Ironically, PHRs' strengths can transform into vulnerabilities if handled inappropriately. The technology's detractors point to several potential disadvantages.

#### A. Disruption of the Physician-Patient Relationship

PHRs can adversely affect the physician-patient relationship and thus undermine transparency in several ways. First, patients who send secure messages to their doctors may expect immediate responses. Doctors who do not check their messages frequently or do not have time to answer all of them in a given day may find that their patients are frustrated and disappointed.<sup>24</sup>

Second, PHRs may induce patients to avoid scheduling appointments even when they would benefit from an in-person visit. Patients may prefer to have many of their health questions answered electronically without the hassle or expense of a doctor's appointment. Yet, in many cases, an old-fashioned examination would be a much more effective diagnostic or follow-up tool, and doctors who merely provide a brief answer in a message would not serve their patients well.<sup>25</sup>

Finally, data release policies pose a particularly significant challenge for physicians. Some medical practices believe that all health information belongs to the patient and should be released as soon as possible even if it is bad news.<sup>26</sup> Indeed, a patient who can digest upsetting news on her own, receive emotional support from family and friends, research her condition and devise appropriate questions before seeing her doctor might have a much more productive discussion during the office visit.

On the other hand, patients who learn of abnormal test results or serious diagnoses by logging into the computer at home rather than through a conversation with a clinician could be traumatized, misunderstand information, or feel angry or hopeless. Such patients might be too frightened to pursue appropriate medical care, become discouraged, fail to comply with their treatment protocols, and suffer medical setbacks.<sup>27</sup>

In fact, some individuals do not welcome pressure to become active members of their own medical team. Humorist Dave Barry typified this approach when he wrote, "I don't WANT

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<sup>24</sup> Miller et al., *supra* note 3.

<sup>25</sup> *Id.*

<sup>26</sup> Sarah A. Collins et al., *Policies for Patient Access to Clinical Data via PHRs: Current State and Recommendations*, 18 J. AM. MED. INFOR. ASSOC. Suppl. 1, i2, 25 (2011).

<sup>27</sup> Thompson et al., *supra* note 10, at 228 (stating that "[a]nother recurring theme was fear of accessing unwanted or frightening information.").

to be an informed medical consumer. I liked it better when my only medical responsibility was to stick out my tongue.”<sup>28</sup>

Consequently, some health care providers are more paternalistic and post test results selectively. However, if physicians decide to screen and withhold certain information from PHRs, patients who are eager to receive any and all information immediately may be resentful and lose trust in their doctors. In addition, patients who are unaware of physicians’ data release practices may be misled by the absence of information. They may think that they are well because no bad news was posted when in fact data was withheld because they are gravely ill.

Furthermore, if providers share candid and complete progress notes, including personal impressions, with patients, patients who are unhappy with their physicians’ conclusions could become less cooperative or trusting of their doctors.<sup>29</sup> If they become acutely aware that what they tell their doctor becomes part of their documentation, patients may also become less open with their doctors. They may avoid disclosing embarrassing or unflattering information that they would not want recorded in their permanent medical charts.

Doctors’ behavior may itself be influenced by the fact that patients can see their notes. They may keep their audience very much in mind in the process of documentation and compose more guarded, “watered down” notes than they otherwise would.<sup>30</sup> The opposite may also be true, however, as doctors who know that patients will read their notes may be more thoughtful and responsible about what they write.

## **B. Increased Workload and Decreased Income for Physicians.**

PHRs can increase clinicians’ workload and adversely affect their earnings. They may find that they spend a lot of time answering secure messages, especially if patients abuse the privilege and inundate their doctors with questions.<sup>31</sup> Because time spent on electronic communication is not reimbursed by insurers,<sup>32</sup> this activity may come at the cost of more lucrative pursuits, such as more patient appointments. In addition, patients may often resort to messaging their doctors in order to obtain free care rather than requesting office visits, and this tendency can further diminish physicians’ earnings.<sup>33</sup>

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<sup>28</sup> Dave Barry, *Good for What Ails You*, MIAMI HERALD, June 21, 1998, available at <http://www.miamiherald.com/living/liv-columns-blogs/dave-barry/article2532166.html>.

<sup>29</sup> John Halamka, et al., *Early Experiences with Personal Health Records*, 15 J. AM. MED. INFORM. ASSOC. 1, 3-5 (2008).

<sup>30</sup> Jan Walker et al., *The Road toward Fully Transparent Medical Records*, 370 N. ENGL. J. MED. 6, 6-8 (2014).

<sup>31</sup> Taylor Pressler Vydra et al., *Diffusion and Use of Tethered Personal Health Records in Primary Care*, 12 PERSPECT. HEALTH INF. MANAG. (Spring 2015),

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4696089/pdf/phim0012-0001c.pdf>.

<sup>32</sup> *Id.*

<sup>33</sup> Miller et al., *supra* note 3.

It should be noted that to date there is little evidence that PHRs have added significantly to physicians' work obligations.<sup>34</sup> This may be attributable to the limited uptake of PHR technology thus far.<sup>35</sup> Yet, while physicians express concern about the eventual workload consequences of PHRs, their fears may be exaggerated.

### C. Exacerbated Health Disparities

PHRs have the potential to be health equalizers by making more information available to all patients. In reality, however, they may exacerbate health disparities.

Patients who are not highly educated or skilled in computer use may not feel comfortable using patient portals.<sup>36</sup> Commentators have noted that in clinics with underserved patient populations, portal use is particularly low.<sup>37</sup> Likewise, people with disabilities and the elderly may be unable to take advantage of PHRs because of physical or mental limitations. If physicians rely on PHRs to communicate with patients, those who do not use them (often members of vulnerable populations) will be significantly disadvantaged.

### D. Compromised Data Accuracy

Some PHRs enable patients to enter information such as home monitoring activities into the system themselves. However, patient-generated information may be incomplete or inaccurate.<sup>38</sup> Patients may misunderstand instructions regarding data entry, measure values incorrectly, or have confusion or dementia that affects their ability to work with PHRs. Physicians who rely on self-entered information to make treatment decisions must keep these uncertainties in mind.

An additional problem is that contemporary EHR systems often are not interoperable.<sup>39</sup> This means that systems operated by different medical practices cannot communicate with each other or integrate each others' records. Without interoperability, patients' records are fragmented and pieces of them are operated and stored by a number of different facilities.<sup>40</sup> Such PHRs will not provide patients with a comprehensive view of their health and may be confusing, incomplete, and even inconsistent.

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<sup>34</sup> Pessler et al., *supra* note 31 (stating that “the effect of PHRs on physician workload is currently unestablished”); Lynn E. Keplinger et al., *Patient Portal Implementation: Resident and Attending Physician Attitudes*, 45 FAM MED. 335, 335 (2013) (reporting that a small study at a single institution revealed that only 13% of respondents felt that their workload had increased).

<sup>35</sup> See *supra* notes 3-4 and accompanying text.

<sup>36</sup> Lester, *supra* note 15 (stating that “[l]imitations of health literacy and competency have been a paramount concern affecting the use of PHRs).

<sup>37</sup> Miller et al., *supra* note 3.

<sup>38</sup> Norm Archer et al., *Personal Health Records: a Scoping Review*, 18 J. AM. MED. INFORM. ASSOC. 515, 516 (2011).

<sup>39</sup> HOFFMAN, *supra* note 23, at 54-55 (discussing interoperability).

<sup>40</sup> Lester, *supra* note 15 stating that “[i]nteroperability is a substantial issue that needs to be addressed for seamless use of PHRs among providers and patients.”).

## E. Diminished Data Security

PHRs can render patient data less secure if patients are not security-conscious. Patients who too freely reveal their passwords or do not store them in a safe place may render their medical information accessible to people with whom they would prefer not to share it.

In addition, patient portals are an entryway to EHR systems. If they are hacked, all the records in the providers' system may be vulnerable to disclosure.<sup>41</sup> It should be noted that non-tethered PHRs may be particularly vulnerable to attack if they are not subject to the security mandates of the HIPAA Security Rule. HIPAA governs only health care providers, health insurers, healthcare clearinghouses, and their business associates.<sup>42</sup> PHRs operated by commercial entities that do not fall into any of these categories may have lax security measures.<sup>43</sup>

## F. Added Liability Concerns

Health care providers have expressed anxiety that PHR use can lead to legal liability.<sup>44</sup> Indeed, those who are not careful in implementing PHRs may face legal claims.

**Online Communication.** Mishandling secure messaging can lead to patient harm and ultimately to litigation.<sup>45</sup> A patient, for example, might send a message to her doctor stating that she is experiencing difficulty breathing. If the physician does not quickly respond, the patient might incorrectly assume that the doctor does not think her condition is potentially serious and conclude that she does not need urgent medical attention. If the patient is in fact having a medical emergency, her reliance on electronic communication and unrealistic belief that her doctor is checking it constantly might have catastrophic consequences. Clinicians who do not educate patients about proper and improper secure messaging use, whose patients do not comply with such instructions, or who do not have qualified staff members read messages frequently, might thus face malpractice claims.<sup>46</sup>

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<sup>41</sup> David Daglish and Norm Archer, *Electronic Personal Health Record Systems: A Brief Review of Privacy, Security, and Architectural Issues*, in PROCEEDINGS OF THE 2009 WORLD CONGRESS ON PRIVACY, SECURITY, TRUST AND THE MANAGEMENT OF E-BUSINESS 110-20 (2009); Kyungsook Kim & Eun-shim Nahm, *Benefits of and Barriers to the Use of Personal Health Records (PHR) for Health Management among Adults*, 16 no. 3 ONLINE J. NURS. INFORMATICS 16 (2012), available at <http://ojni.org/issues/?p=1995>; HOFFMAN, *supra* note 23, at 56-79 (discussing data security and the HIPAA Security Rule).

<sup>42</sup> 45 C.F.R. §§ 160.102-160.103 (2016); 42 U.S.C. §17934 (2010).

<sup>43</sup> Wynia & Dunn, *supra* note 5, at 70.

<sup>44</sup> Lester, *supra* note 15, at 12; Jana Studeny & Alberto Coustasse, *Personal Health Records: Is Rapid Adoption Hindering Interoperability?*, 11 PERSPECTIVES IN HEALTH INFO. MANAGEMENT (Summer 2014), <http://perspectives.ahima.org/personal-health-records-is-rapid-adoption-hindering-interoperability/>.

<sup>45</sup> Madhavi R. Patt et al., *Doctors Who Are Using E-mail With Their Patients: A Qualitative Exploration*, 5 J. MED. INTERNET RES. e9 (2003) (stating that doctors are concerned about e-mails reaching them in a timely fashion); Paul Rosen and C. Kent Kwok, *Patient-Physician E-mail: An Opportunity to Transform Pediatric Health Care Delivery*, 120 PEDIATRICS 701, 705 (2007) (stating that e-mail communication might produce anxiety about increased liability).

<sup>46</sup> Daniel Z. Sands, *Help for Physicians Contemplating Use of E-mail with Patients*, 11 J. AM. MED. INFORM. ASSOC. 268, 268 (2004).

Doctors who enable patients to use secure messaging but are unresponsive to electronic communication may be more likely to be sued than doctors who do not offer this feature at all. Multiple studies have shown that patients most often decide to sue when they are displeased with the quality of the physician-patient relationship, including their communication experiences.<sup>47</sup>

No reported medical malpractice case arising from secure messaging (or regular e-mail) could be found as of 2016. However, doctors have been sued for failure to respond appropriately to phone calls.<sup>48</sup> It is only a matter of time before similar claims involving electronic communication will arise.

***Other Bases for Malpractice Claims.*** Several other PHR pitfalls may generate liability concerns. Individuals who misinterpret their PHR data or become traumatized by posted test results may not seek appropriate care or comply with their treatment plans.<sup>49</sup> Poor outcomes that result from such behavior may lead to malpractice claims that could have been avoided with more personal contact between clinicians and patients. Even if these claims ultimately prove unjustified, they can be distressing and costly for defendants.

Health care providers who rely on patient-entered data (e.g. blood pressure or blood sugar levels) for purposes of treatment decisions may make mistakes when the data are inaccurate. Courts may not be receptive to the argument that resulting harm is the patient's fault and may expect doctors to verify PHR entries.<sup>50</sup>

Similarly, if secure messaging does substantially increase physicians' workloads, doctors may be more rushed and fatigued during their workdays. This too could contribute to medical errors that harm patients.

***Data Security.*** PHRs are a user interface that can be hacked, and therefore, they are another avenue of attack for wrongdoers. Health care providers whose EHR systems' security is compromised through PHRs may face HIPAA enforcement actions and privacy-related tort claims.

The HIPAA Privacy Rule establishes breach notification requirements along with civil and criminal penalties for data breaches.<sup>51</sup> Although the HIPAA Privacy Rule does not feature a private right of action, plaintiffs who believe they suffered privacy harms may turn to state statutory and common law tort theories.<sup>52</sup>

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<sup>47</sup> Beth Huntington & Nettie Kuhn, *Communication Gaffes: A Root Cause of Malpractice Claims*, 16 BAYLOR UNIV. MED. CENTER PROC. 157, 157-60 (2003).

<sup>48</sup> *Kaznowski v. Biesen-Bradley*, No. C063872, 2012 WL 5984491 (Cal. Ct. App. Nov. 30, 2012); *Lemlek v. Israel*, 161 A.D.2d 299, 301 (1990), modified, 577 N.E.2d 1041 (1991).

<sup>49</sup> See *supra* notes 26-29 and accompanying text.

<sup>50</sup> Tang, *supra* note 5 at 125 (stating that "courts might apply negligence standards in cases where practitioners rely on inaccurate patient-entered PHR information to make suboptimal decisions about care.").

<sup>51</sup> 45 C.F.R. §§ 164.400-.414 (2016); 42 U.S.C. §§ 1320d-5 & 1320d-6 (2010).

<sup>52</sup> HOFFMAN, *supra* note 23, at 75-78, 93-95.

## IV. Recommendations

There is no easy answer to the question of how PHRs can best be used. Formulating a comprehensive blueprint for PHR implementation is well beyond the scope of this chapter. The following are a few suggestions for handling some of the key PHR challenges.

### A. Secure Messaging Policies

The American Medical Association has issued guidance concerning physicians' use of electronic communication.<sup>53</sup> It advises in relevant part:

- a) Uphold professional standards of confidentiality and protection of privacy, security, and integrity of patient information.
- b) Notify the patient of the inherent limitations of electronic communication, including possible breach of privacy or confidentiality, difficulty in validating the identity of the parties, and possible delays in response. Such disclaimers do not absolve physicians of responsibility to protect the patient's interests. Patients should have the opportunity to accept or decline electronic communication before privileged information is transmitted. The patient's decision to accept or decline email communication containing privileged information should be documented in the medical record.
- c) Advise the patient of the limitations of these channels when a patient initiates electronic communication.
- d) Obtain the patient's consent to continue electronic communication when a patient initiates electronic communication.
- e) Present medical information in a manner that meets professional standards.

The British Medical Protection Society adds the following advice:

- Liaise with your IT provider to ensure that appropriate safeguards are in place and information on the clinical system remains secure.
- Have an automated response indicating that the email has been received, when the patient should expect to receive a reply and a recommendation that they should contact the practice directly if the matter is urgent.
- Monitor email enquiries at regular intervals and ensure that they are promptly brought to the attention of the relevant person.

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- [Do not] [f]orget that email exchanges are an important part of a patient's medical records.

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<sup>53</sup> American Medical Association, *Code of Medical Ethics* §2.3.1, (accessed January 17, 2017), <https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-2.pdf>.

- [Do not] [f]orget that many of the subtleties of communication, including non-verbal cues, are lost when communicating by email.<sup>54</sup>

All of these recommendations are sound, and clinicians would be wise to adopt them.

## **B. Data Release Policies**

Health care providers must develop thoughtful data release policies for their PHRs and clearly explain them to patients so that patients have realistic and well-informed expectations about data access.<sup>55</sup> One option is to exclude entirely certain types of information, such as test results indicating the presence of serious illness, from PHRs. Another option is for physicians to screen and withhold potentially distressing data for a time in order to communicate with patients about it before it is posted. A third alternative is to release all information as soon as it becomes available and assume that patients value transparency above all.<sup>56</sup> Thus far, no approach has been empirically shown to be superior to others.

Because patients have different preferences, a possibility that is well worth considering is to allow patients to tailor their own access to information. Thus, patients would be able to indicate in advance which types of information they would like to see and whether they would want it released immediately or only after speaking with their clinicians.<sup>57</sup> Meaningful use regulations<sup>58</sup> could require that providers ask patients for their preferences. Likewise, EHR system certification regulations<sup>59</sup> could require that PHR technology facilitate this type of flexibility, in part by enabling patients to indicate their access choices and alerting clinicians to them each time they post data.

## **C. Error Correction Policies**

Health Care providers should encourage patients to use PHRs as a means to identify errors in their medical records and request corrections. Patients should be able to ask for changes easily through secure messaging or a separate PHR feature, and providers must be obligated to review and respond to these requests. When providers determine that a request for amendment is unjustified (e.g. because the original information is actually correct), they are permitted by law to deny it.<sup>60</sup>

Researchers have found very high error rates in EHRs because it is easy to mistype information, check or select wrong menu items, copy and paste data that is not updated, and

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<sup>54</sup> Medical Protection Society, *Communicating with Patients by Fax and Email* (Dec. 2014), <http://www.medicalprotection.org/docs/default-source/pdfs/factsheet-pdfs/england-factsheet-pdfs/communicating-by-fax-and-email.pdf?sfvrsn=7>.

<sup>55</sup> Michael A. Bruno et al., *The 'Open Letter': Radiologists' Reports in the Era of Patient Web Portals*, 11 J. AM. COLLEGE RAD. 863, 863 (2014).

<sup>56</sup> Collins et al., *supra* note 26, at i5.

<sup>57</sup> Thompson, *supra* note 10, at 229 (noting that “a minimum waiting period under certain circumstances may be advisable”).

<sup>58</sup> See *supra* note 2 and accompanying text.

<sup>59</sup> 45 CFR § 170.314 (2016).

<sup>60</sup> 45 C.F.R. §164.526(a)(2) (2016).

make a variety of other mistakes.<sup>61</sup> Patients are often in the best position to detect such errors and can play a key role in safeguarding the integrity of their medical records.

#### **D. Patient Education Initiatives**

Patients who are elderly, disabled, economically disadvantaged, or simply disinterested in technology may have poor computer literacy and find it very difficult to use and navigate PHRs.<sup>62</sup> Consequently, providers should offer PHR tutorials through videos or classes that help patients learn to use the technology.<sup>63</sup> In addition, such tutorials could emphasize the importance of PHR security and of double-checking data accuracy for patients who will enter their own health information. They could also furnish guidance concerning appropriate use of secure messaging and requests for error corrections. Though such tutorials will not be effective for all individuals, they would constitute an important step towards increasing patients' comfort and facility with PHR technology.

### **V. Conclusion**

Physicians' PHR policies and data disclosure practices can have wide-ranging impacts on the physician-patient relationship. PHRs can contribute significantly to medical transparency, health record integrity, and patient satisfaction, but they can also do the opposite. For some patients, PHRs will be abstruse and frustrating or even erode their confidence in their doctors. PHRs are a key communication tool for clinicians, and their implementation must be carefully thought-out. PHRs raise significant legal, ethical, and policy questions that have yet to be fully explored and addressed. These challenges deserve careful consideration from the health care community, information technology professionals, and health policy authorities.

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<sup>61</sup> HOFFMAN, *supra* note 23, at 23-27.

<sup>62</sup> Lester, *supra* note 15 (stating that “[l]imitations of health literacy and competency have been a paramount concern affecting the use of PHRs.”).

<sup>63</sup> *Id.*; Thompson, *supra* note 10, at 229.