

## Electronic Medical Records – Healthy for Whom?

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Reform of how healthcare is delivered, whether through state or federal initiatives, insurer protocols, or provider action, is proceeding rapidly and with insufficient attention to how it affects the recipients of health care. The motivation for health care reform is primarily to control health care costs, and secondarily to improve quality of care. Policy makers have repeatedly touted the efficacy of electronic health records. Electronic health records may have unintended results which are detrimental to patients, and persons with psychiatric challenges in particular.

Providers are encouraged to adopt electronic medical records by state and federal law, and by private and public insurers.<sup>1</sup> While electronic medical records have some merits, persons with psychiatric challenges have a legitimate concern about their adoption.<sup>2</sup> Persons with psychiatric

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<sup>1</sup> Health Information Technology for Economic and Clinical Health (HITECH) Act, 42 U.S.C. § 13101- 13424 (2012). The HITECH Act of 2009 essentially mandates that physicians and hospitals adopt electronic records by 2014, or face penalties in the form of reduced Medicare/Medicaid payments. *Id.* The Patient Protection and Affordable Care Act also encourages the adoption of electronic health records, partially for research purposes and partially for the delivery of health care services. 42 U.S.C. § 18001 et seq. (2012). Section 108 of Chapter 224 of the Massachusetts Acts of 2012 requires doctors to demonstrate proficiency in electronic health records to be licensed. Act of Aug. 6, 2012, ch. 224, § 108, 2012 Mass. Acts.

<sup>2</sup> See Otto F. Wahl, *Mental Health Consumers' Experience of Stigma*, 25 SCHIZOPHRENIA BULLETIN 467, 467-78 (1999). In a survey of 1,301 mental health consumers, the majority tried to conceal their illnesses due to associated stigma and "worried a great deal that others would find out about their psychiatric status and treat them unfavorably." *Id.* at 467. Strong verification of this point comes from mental health clinicians themselves; the majority of those surveyed for one recent study said they would not want their own personal psychiatric record included with their general medical record. See Ronald M. Salomon et al., *Openness of Patients' Reporting With Use of Electronic Records: Psychiatric Clinicians' Views*, 17 J. AM. MED. INFO. ASS'N, 54-60 (2010). The Massachusetts legislature was familiar with the social, vocational, familial, legal, physical wellness and psychiatric consequences of the release of similar types of health care information when it barred such disclosures as a matter of law. See MASS. GEN. LAWS ch. 111, § 70F (2012) (barring disclosure of HIV/AIDS test results); § 70G (barring disclosure of genetic testing); 105 MASS. CODE REGS. 127.020 (D) (barring disclosure of mammogram reports). The concern of persons with psychiatric diagnoses is not primarily about rampant security breaches, although they do exist. See, e.g., Nicole Perlroth, *Digital Data on Patients Raises Risk of Breaches*, N.Y. TIMES, Dec. 18, 2011 at B2; Patrick Ouellette, *Heartbleed Bug Lessons Learned: Having a Remediation Plan*, HEALTH IT SECURITY (April 28, 2014), <http://healthitsecurity.com/2014/04/28/heartbleed-bug-lessons-learned-having-a-remediation-plan>. See generally, *Breaches Affecting 500 or More Individuals*, U.S. DEP'T. OF HEALTH & HUMAN SERVS., [https://ocrportal.hhs.gov/ocr/breach/breach\\_report.jsf](https://ocrportal.hhs.gov/ocr/breach/breach_report.jsf) (last visited April 7, 2015). Medical records are an

challenges are concerned about electronic health records because electronic health records facilitate the sharing of information, and persons with psychiatric challenges lack control over which of their health care providers may see their psychiatric information.<sup>3</sup> Of course, the more persons with whom information is shared, the greater the likelihood of unauthorized releases of private information. The larger concern, however, is not about these illegal disclosures, but rather about disclosures permitted by state and federal law.<sup>4</sup> The Health Insurance Portability and Accountability Act (“HIPAA”) Privacy Rule provides insufficient protection of mental health information as it only prevents disclosure of psychotherapy notes without patient consent.<sup>5</sup> The Privacy Rule narrowly defines psychotherapy notes as “notes recorded by a [mental health professional] documenting or analyzing the contents of conversation during a private counseling session or a group, joint, or family counseling session and that are separate from the rest of the [patient’s] medical record.”<sup>6</sup> Thus, the Privacy Rule permits disclosure to any person providing health care to a patient, *without the patient’s authorization*, of the following mental health medication prescription and monitoring, counseling session start and stop times, modalities and frequency of treatment furnished, results of clinical tests, and any summary of diagnosis, functional

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unusually attractive target of hackers, as they reap more on the Internet black market than other personal information. *See* Dan Tynan, *The Next Data Theft Target: Your Medical Records*, YAHOO! TECH, (Feb. 18, 2014), <https://www.yahoo.com/tech/the-next-data-theft-target-your-medical-records-77113382628.html>. The medical records of nearly 30 million Americans have been compromised since 2009. Jeff Goldman, *30 Million Americans Affected by Medical Data Breaches Since 2009*, ESECURITY PLANET (Feb. 17, 2014), <http://www.esecurityplanet.com/networksecurity/30-millionamericans-affected-by-medical-data-breaches-since-2009.html>.

<sup>3</sup> Wahl, *supra* note 2, at 467. Patients with psychiatric conditions may be concerned about the stigma associated with mental health conditions. *Id.*

<sup>4</sup> *See id.*

<sup>5</sup> *See* 45 C.F.R. §§ 164.102 – 164.106 (2013) (defining security and privacy); 45 C.F.R. §§ 164.500 – 164.532 (2013) (regulating protected information).

<sup>6</sup> *See* 45 C.F.R. § 164.501.

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status, treatment plan, symptoms, prognosis, and progress to date.<sup>7</sup>

Most people presume that sharing medical records will enhance quality of care.<sup>8</sup> However, for persons with psychiatric diagnoses, this is often not the case.<sup>9</sup> In fact, due to stigma, providers often give poorer health care to persons whom they know or infer have psychiatric diagnoses.<sup>10</sup> Stigma against persons with psychiatric histories exists in the medical profession. Physicians, psychiatrists, nurses, other mental health professionals, and medical/mental health students are among those who manifest stigmatizing bias.<sup>11</sup> Nurses, according to researchers, can act as

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

<sup>8</sup> See Nir Menachemi and Taleah H. Collum, *Benefits and Drawbacks of Electronic Health Record Systems*, 4 RISK MGMT. HEALTHCARE POL'Y 47 (2011), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3270933/pdf/rmhp-4-047.pdf>.

In general, the impact of health IT is mixed. One study of hospitals found that “health IT does not impact outcomes for patients with mean severity,” while health IT “reduces mortality for those pneumonia patients requiring more care coordination and those with greater information management requirements” and those patients with acute myocardial infarction (AMI) whose comorbidities require coordination across multiple specialties. No such reduction in mortality was found for other AMI patients. J. McCullough et al., *Health information technology and patient outcomes: the role of information and labor coordination*, 47 RAND J. ECO. 207 (2016). The same article cites five studies between 2010 and 2014 that found no impact of health IT on average hospital quality and one that found a modest decrease in infant mortality when birth certificate records were linked to county-level health IT adoption rates. *Id.* Smaller practices also have inconsistent results in achieving quality measures after the adoption of electronic health records. C. McCullough, et al., *Quality Measure Performance in Small Practices Before and After Electronic Health Record Adoption*, 3eGEMs (Generating Evidence & Methods to improve patient outcomes) 2015, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4371508/pdf/egems1131.pdf> (last accessed Oct. 25, 2016).

<sup>9</sup> See Graham Thornicroft et al., *Discrimination in Health Care Against People with Mental Illness*, 19 INT'L REV. PSYCHIATRY 113 (2007). “There is strong evidence that people with a diagnosis of mental illness, for example, have less access to primary health care and also receive inferior care for diabetes and heart attacks. . . .” (*citations omitted*). *Id.* at 118. See also M. Heron, et al., *Deaths: Final Data for 2006*, 57 NAT'L VITAL STATISTICS REPORTS (April 2009), available at [http://www.cdc.gov/nchs/data/nvsr/nvsr57/nvsr57\\_14.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr57/nvsr57_14.pdf). Life expectancy for people with major mental illness is 56 years while the “average” American life expectancy is 78 years. *Id.*

<sup>10</sup> Thornicroft, *supra* note 9 (discussing discrimination in health care against people with mental illness); S. Jeffery, *Psychiatrists Not Immune to Mental Health Bias*, Medscape (May 21, 2013)(report on inferior physical health care delivered to persons with serious mental illness delivered as Abstract NR12-12, American Psychiatric Association's 2013 Annual Meeting). Among all physicians who said bias affected treatment, 72% said that emotional problems had a negative effect on treatment. C. Peckham, *Medscape Psychiatry Lifestyle Report 2016: Bias and Burnout 2016*, Slide 7, available at <http://www.medscape.com/features/slideshow/lifestyle/2016/psychiatry> (last accessed April 13, 2016).

<sup>11</sup> See generally, Allison L. Smith & Craig S. Cashwell, *Stigma and Mental Illness: Investigating Attitudes of Mental Health and Non-Mental Health Professionals and Trainees*, 49 J. HUMANISTIC COUNSELING, EDUC. AND DEV. 189, 189-202 (2010); A. Llerena et al., *Schizophrenia stigma among medical and nursing undergraduates*, 17 EUR. PSYCHIATRY 298, 298-99 (2002); H. Rao et al., *A Study of Stigmatized Attitudes Towards People with*

“stigmatizers” because they believe that individuals with mental health issues are dangerous, weak and to blame information for symptoms.<sup>12</sup> They often do not respect or give credence to patients with psychiatric diagnoses, believing them to be poor historians, unreliable, and uncooperative.<sup>13</sup>

Partially as a result of this stigma, persons with psychiatric histories on average die twenty-five years earlier than the general population and sixty percent of those who die prematurely die of preventable or treatable conditions.<sup>14</sup> Cardiovascular disease is the predominant cause of premature death among this population, and many studies have shown that individuals with psychiatric histories tend to receive less care when they present with symptoms of cardiovascular disease.<sup>15</sup>

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*Mental Health Problems Among Health Professionals*, 16 J. OF PSYCHIATRIC AND MENTAL HEALTH NURSING 279, 279-84 (2009); M. Hugo, *Mental Health Professionals' Attitudes Towards People Who Have Experienced a Mental Health Disorder*, J. OF PSYCHIATRIC AND MENTAL HEALTH NURSING, 419, 419-25 (2001); Jeffery, *supra* note 10.

<sup>12</sup> See generally C. A. Ross & E.M. Goldner, *Stigma, Negative Attitudes and Discrimination Towards Mental Illness within the Nursing Profession: A Review of the Literature*, 16 J. OF PSYCHIATRIC AND MENTAL HEALTH NURSING 558, 558-67 (2009).

<sup>13</sup> See *id.* The disbelief of patients with psychiatric diagnoses is even more concerning as doctors rely more heavily on clinical decision support systems (CDSS). For instance, a study of Brigham and Women's CDSS found that four errors in the CDSS went undiscovered, one for over a year and one that led to the suggestion of ordering anti-platelet medication for those already taking it. Adam Wright, *et al.*, *Analysis of Clinic Decision Support System Malfunctions: a case series and survey*, J. AM. MED. INFORM. ASSOC. (Oxford Univ. Press 2016). (Of the 29 Chief Information Medical Officers responding to the authors' survey, only two did not report an error in their CDSS in the past year.) A person with a psychiatric diagnosis who objects to taking additional medication recommended by a CDSS is more likely to be ignored than a patient without such a diagnosis.

<sup>14</sup> See *supra* note 9 (discussing life expectancy of individuals with mental illness). See generally Babak Roshanaei-Moghaddam & Wayne Katon, *Premature Mortality From General Medical Illnesses Among Persons With Bipolar Disorder: A Review*, 60 Psychiatric Services 147, 147-54 (2009) (discussing recent evidence which has shown an increased risk of premature mortality for bipolar patients). A study that used the Western Australian Linked Database, found that persons with mental illness have mortality rates that are 2.5 times higher than the general population. David Lawrence & Rebecca Coghlan, *Health Inequalities and the Health Needs of People with Mental Illness*, 131 NSW PUBLIC HEALTH BULLETIN 155 (2002). A more recent study found persons with bipolar disorder had double the all-cause risk of death than the general population, and natural deaths are 1.5 times greater. Joseph Hayes, *et al.*, *A systematic review and meta-analysis of premature mortality in bipolar affective disorder*, 131 Acta Psych. Scandinavia 417 (2015). The review looked at data from 1935 to 2010 and found that all-cause mortality for persons with bipolar disorder has improved over time. *Id.* at 424.

<sup>15</sup> See BARBARA MAUER, NAT'L ASS'N OF STATE MENTAL HEALTH PROGRAM DIRS. MED. DIRS. COUNCIL, MORBIDITY AND MORTALITY IN PEOPLE WITH SERIOUS MENTAL ILLNESS 4, 6-7, 11-15 (Joe Parks et al. eds. 2006). Sixty percent of premature deaths in persons with serious mental illness are due to “natural causes,” the front-runner being cardiovascular disease. *Id.* at 4, 11-15; see also Hayes, *supra* note 14 (persons with bipolar disorder have double the risk of death from circulatory illnesses than the general population).

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The impact of stigma on the quality of care of persons with psychiatric histories is not limited to cardiac conditions.<sup>16</sup> Clinician bias against persons with mental illness often adversely affects medical management and leads to poor quality care.<sup>17</sup> In order to learn more about this disparity, Massachusetts' Behavioral Health Task Force held public forums on the topic.<sup>18</sup> Numerous

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These persons face problems such as patient fearfulness, system fragmentation, and significantly, provider stigma, in accessing health care for treatable conditions. MAUER at 6-7. In fact, persons with serious mental illness have lower rates of cardiovascular procedures compared to the general population for these reasons. *Id.* at 7. In one study of patients presenting with chest pain, for example, only 40% of patients with behavioral or mental health diagnosis were referred for coronary angioplasty. See Susan Jeffrey, *Psychiatrists Not Immune to Mental Health Bias*, MEDSCAPE (May 21, 2013), <http://www.medscape.com/viewarticle/804499#1>. In addition, persons with a serious mental illness and a cardiovascular condition receive about half the number of follow-up interventions, such as bypass surgery or cardiac catheterization, following a heart attack than do normal cardiac patients with no serious mental illness. See Juliann Garey, *When Doctors Discriminate*, N.Y. TIMES (Aug. 11, 2013), [http://www.nytimes.com/2013/08/11/opinion/sunday/when-doctorsdiscriminate.html?pagewanted=all&\\_r=0](http://www.nytimes.com/2013/08/11/opinion/sunday/when-doctorsdiscriminate.html?pagewanted=all&_r=0). See also, C. Woodhead, et al., *Cardiovascular disease treatment among patients with severe mental illness: a data linkage study between primary and secondary care*, BR. J. GEN. PRAC. (June 2016) (Study found a significant shortfall in the prescription of beta blockers and ACE inhibitors or angiotensin receptor blockers for persons with serious mental illness and heart failure/coronary heart disease. The shortfall could not be accounted for by number of visits with doctors.)

<sup>16</sup> See, e.g., MAUER, *supra* note 15, at 24 (explaining diabetics with mental disorders do not receive standard of care diabetic monitoring); Casey A. Boyd et al., *The effect of depression on stage at diagnosis, treatment, and survival in pancreatic adenocarcinoma*, 152 SURGERY 403 (2012) (national, population-based study shows that pre-existing depression in patients with pancreatic cancer is associated with advanced stage at diagnosis, decreased likelihood of receiving adequate treatment, and poor survival). A British study did not find that mental health diagnoses overall resulted in late stage diagnosis of cancer, but nonetheless did find that survival rates were much lower than persons without mental health disorders. The finding of diminished survival rates for persons with psychiatric diagnoses is mirrored in Swedish, Canadian, Australian and United States studies. At least some of the reduction in survival rate is due to fewer interventions, like surgery and chemotherapy. C. Chang, et al., *A cohort study on mental disorders, stage of cancer at diagnosis and subsequent survival*, BMJ Open 2013 (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3913023/> last accessed Oct. 25, 2016). The articles, while not providing a definitive conclusion, notes studies in other countries that found later or no diagnosis of cancer for persons with mental health diagnoses: Australia - higher proportion of metastasis at cancer presentation for psychiatric patients than general population, especially breast and lung cancer ; United States – later diagnosis of colon cancer (49.7% vs. 53.3%) or no diagnosis at death (4.4% vs. 1.1%); and United States – history of major depression associated with a delayed diagnosis of breast cancer resulting in an almost ten-fold increased risk. *Id.*

<sup>17</sup> See Jeffrey Jackson & Kurt Kroenke, *Difficult Patient Encounters in the Ambulatory Clinic: Clinical Predictors and Outcomes*, 159 ARCH. INTERN. MED. 1069, 1072-73 (1999); Mark Graber et al., *Effect of a Patient's Psychiatric History on Physicians' Estimation of Probability of Disease*, 15 J. GEN. INTERN. MED. 204 (2000); Lawrence, *supra* note 14, at 157. Mental disorder is a predictor of patient encounters being perceived as "difficult" by clinicians, and this perception has negative care consequences. Jackson, *supra*, at 1069, 1072. One survey of 300 family physicians determined that "past psychiatric history influences physicians' estimation of disease presence and willingness to order tests." Graber, *supra*. Recognizing that stigma is one root of the "difficulty" problem, it has been argued that "[i]t is possible that difficulty could be reduced by recognizing and treating mental disorders and by improving physician skills or attitudes toward addressing psychosocial problems or patient's serious illness concerns." Jackson, *supra*, at 1073.

<sup>18</sup> See BEHAVIORAL HEALTH INTEGRATION TASK FORCE, REPORT TO THE LEGISLATURE AND THE

persons with psychiatric challenges recounted their inability to get appropriate physical health care because their providers were aware of their psychiatric histories.<sup>19</sup>

Reports from people with psychiatric histories on their experiences with health care providers ranged from ordinary rudeness to refusal to treat serious medical conditions ultimately confirmed as real.<sup>20</sup> In the experience of people with mental health diagnoses, some clinicians incorrectly attribute physical symptoms to psychiatric conditions because they tend to generalize negatively about the capacity of people with mental illness to describe physical symptoms reliably.<sup>21</sup> One article notes people with mental illness:

reported professionals as being dismissive or assuming that physical presentations were “all in the mind”. This can result in reluctance to return for further visits, which can have a detrimental effect on physical health. This is especially significant, as evidence suggests people with mental illness are at greater risk from physical health problems, including cardiovascular disease, diabetes, obesity and respiratory disease. . . .<sup>22</sup>

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HEALTH POLICY COMMISSION 69 (2013) (listing Behavioral Health Integration Task Force forums, including April 30, 2013 communication and privacy forum). The task force was established under Chapter 224, Section 275 of the Massachusetts Acts and Resolves of 2012 to provide recommendations to the legislature on behavioral and mental health care treatment and service delivery. Act of Aug. 6, 2012, ch. 224, § 108, 2012 Mass. Acts 901.

<sup>19</sup> See BEHAVIORAL HEALTH INTEGRATION TASK FORCE, *supra* note 18, at 82, 85-86 (summarizing comments regarding privacy of mental health electronic medical records).

<sup>20</sup> See generally Peter Byrne, *Stigma of Mental Illness and Ways of Diminishing It*, 6 ADVANCES IN PSYCHIATRIC TREATMENT 65 (2000) (stating “[a]ny list of stigmatizers includes. . . health care professionals.”). Byrne also notes a study showing that psychiatrists themselves are not immune to prejudice based on a mental health diagnosis, as evidenced by increased value judgments and diagnostic differences once a person had been labeled with a particular mental health diagnosis. *Id.* at 68-69.

<sup>21</sup> See e.g., E. Koranyi, *Morbidity and Rate of Undiagnosed Physical Illnesses in a Psychiatric Clinic Population*, 36 ARCH. GEN. PSYCHIATRY 414-19 (1979). In a study of 2,090 psychiatric patients, 43% suffered from at least one major medical illness, of which, almost half or 46% remained undiagnosed by the referring physician. *Id.* See also Wahl, *supra* note 2. One interviewee commented on her medical school experience: “The treatment of psych patients in all rotations was awful. They would laugh at them, poke fun at them on rounds, disbelieve any physical complaint they had.” *Id.* See also, Lawrence, *supra* note 14, at 157 (noting mental health practitioners “may regard complaints of physical illness as psychosomatic.”)

<sup>22</sup> See S. Parle, *How does discrimination affect people with mental illness?* 108 NURSING TIMES 28:12-14 (2012) (citations omitted). Another study indicates that persons with psychiatric diagnoses who experience discrimination in the health care system may incur higher health care costs, and a reduction over time in health care use and leisure activities that can assist recovery. B. Osumili, *The economic costs of mental health-related discrimination*, 134 ACTA PSYCHIATR. SCAND. Sup. 446, 34 (2016). See also, S. Evans-Lacko, et al., *How much does mental health discrimination cost: valuing experienced discrimination in relation to healthcare care costs and community*

Several studies also demonstrate the prevalence of this failure to appropriately treat persons with mental illness.<sup>23</sup> One study of 1,953 patients reviewed inappropriate admissions to psychiatric facilities where physical diagnoses were missed. The vast majority of patients inappropriately admitted (85%) already had mental illness documented in their medical records.<sup>24</sup> The researchers concluded:

the results presented here raise concerns as to whether, in some scenarios, patients with a known history of mental illness receive the medical assessment and treatment they need, or if, in some cases, their physical symptoms are misattributed to their mental illness.<sup>25</sup>

Another study confirmed that documentation of a past psychiatric diagnosis contributes to an incorrect diagnosis of delirium, which often is due to such factors as a severe or chronic medical illness, medication, infection, surgery, or drug or alcohol abuse.<sup>26</sup> Veteran's Administration

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*participation.* 24 EPIDEMIOL. AND PSYCHIATR. SCI. 423 (2015)(Cost of health services used for individuals who reported previous experiences of discrimination in a healthcare setting was almost twice as high as for those who did not report any discrimination during the last 12 months and this was maintained after controlling for symptoms and functioning.)

<sup>23</sup> In one study, approximately 80% of persons brought to a psychiatric research ward had physical illness requiring treatment that had been undiagnosed by their physicians, more than half of which either caused or greatly exacerbated these patients' psychiatric conditions. R. Hall, *Physical Illness Manifesting as Psychiatric Disease*, 37 ARCH. GEN. PSYCHIATRY 989-95 (Sept. 1980). One hundred patients were intensively evaluated for the presence of unrecognized medical illnesses that might have affected their hospitalization. *Id.* Forty-six percent of these patients suffered from physical, medical illnesses previously undiagnosed by their physician and which physical, medical illnesses either directly caused or greatly exacerbated their psychiatric symptoms. *Id.* An additional 34% of patients were found to be suffering from at least one other undiagnosed physical, medical illness requiring treatment though unrelated to their psychiatric symptoms. *Id.* See also, J.E. Tintinalli, et al., *Emergency Medical Evaluation of Psychiatric Patients*, 23 ANN. EMERGENCY MED., 859, 859-62 (1994). Eighty percent of those "medically cleared" by emergency department for psychiatric hospitalization an illness should have had a physical illness identified. *Id.* See also R.R. Reeves et al., *Inappropriate Psychiatric Admission of Elderly Patients with Unrecognized Delirium*, 103 SOUTHERN MEDICAL JOURNAL, 111-15 (2010) (finding patients in psychiatric rather than medical units less likely to undergo full diagnostic assessment).

<sup>24</sup> Roy R. Reeves et al., *Unrecognized physical illness prompting psychiatric admission*, 22 ANNALS OF CLINICAL PSYCHIATRY 180, 184 (2010), available at [https://www.aacp.com/pdf%2F0810%2F0810ACP\\_Reeves.pdf](https://www.aacp.com/pdf%2F0810%2F0810ACP_Reeves.pdf) (concluding physical symptoms of patient with mental-illness history are more likely attributed to psychiatric-illness).

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

<sup>26</sup> Yasuhiro Kishi et al., *Delirium: Patient Characteristics that Predict a Missed Diagnosis at Psychiatric Consultation*, 29 GEN. HOSPITAL PSYCHIATRY 442 (2007). Past psychiatric diagnosis and pain contributed to missed diagnosis of

doctors who were presented identical vignettes, the only difference being that one person had stable schizophrenia, were less likely to refer the person with schizophrenia for either weight management or a sleep study, though both were indicated.<sup>27</sup>

Further, undue disclosure of psychiatric information can lead to negative public health consequences, including the avoidance of necessary care<sup>28</sup> and the undermining of research results intended to develop treatment and design best practices.

Accurate and complete information cannot be obtained by force. We know from the California HealthCare Foundation's National Consumer Health Privacy Survey of November 9, 2005 that 1/8 patients or 12.5% of the population avoids their regular doctor, asks doctors to alter diagnoses, pays privately for a test, or avoids tests altogether. If we do not restore patient control over [protected health information], we can expect electronic health data to have error and omission rates of up to 12.5%. The breakthroughs and benefits possible with technology-enhanced research will never be replaced with such a high rate of errors and omissions.<sup>29,30</sup>

Another concern is that erroneous and stigmatizing information can be rapidly

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delirium in 46% of psychiatric consultations. *Id.*

<sup>27</sup> Dinesh Mittal, *Understanding Provider Decision-Making*, IIR 08-086, U.S. DEP'T OF VETERANS AFF. (2013).

<sup>28</sup> Teens especially are concerned with privacy. Kenneth Ginsburg, *Earning a Teenager's Trust* (April 1, 2013), available at <http://www.medscape.com/viewarticle/781366>. The willingness of teens to seek and stay in care, as well as disclose sensitive information increases significantly with assurances of confidentiality. Carol A. Ford, et al., *Influence of Physician Confidentiality Assurances on Adolescents' Willingness to Disclose Information and Seek Future Health Care*, 278 J. AM. MED. ASSOC. 1029 (1997). See also, Debra J. Rickwood, et al., *When and how do young people seek professional help for mental health problems?*, 187 MED. J. AUSTRALIA. S35 (2007) "Confidentiality remains of utmost importance when engaging young people, and this is particularly important in the context of accessing alcohol and other drug services." *Id.* at S57. Disclosure of sensitive medical information may lead adults to avoid care or withhold information from providers as well. See William A. Yasnoff, *The Health Record Banking Model for Health Information Infrastructure*, in HEALTHCARE INFO. MGT. SYSTEMS: CASES, STRATEGIES, AND SOLUTIONS 336-37 (C.A. Weaver et al. eds., 2016). The mere use of an EHR system by a mental health therapist during intake both impairs the therapeutic alliance and reduces the likelihood the client will continue care. D. Rosen, et al., *The impact of computer use on therapeutic alliance and continuance in care during the mental health intake*, 53 PSYCHOTHERAPY 117 (2016).

<sup>29</sup> *Ensure "Meaningful Use" by Giving Consumers Control*, CONSUMER ACTION (June 2009), <http://www.privacy-information.org/articles/ensure-meaningful-use-by-giving-consumers-control-over-their-health-inform>.

<sup>30</sup> The fact that a provider uses an electronic records system increases the likelihood that a patient will withhold information, particularly if the patient has a stigmatizing health condition like mental illness. C. Campos-Castillo and D. Anthony, *The double-edged sword of electronic health records: implications for patient disclosure*, 22 J. Am. Med. Inform. Assoc. e130, e137(2015).

distributed.<sup>31</sup> Because diagnoses and medications are not protected from other providers, this information may be peppered throughout one's medical records, even when erroneous, outdated, or irrelevant to the presenting issue or particular provider. In addition, state and federal law unfortunately impedes the ability of persons with psychiatric histories to correct errors by permitting providers to limit patient access to certain mental health records.<sup>32</sup>

Electronic medical records do not necessarily improve health care.<sup>33</sup> Because electronic

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<sup>31</sup> P. Hsieh, *Can You Trust What's in Your Electronic Medical Records?* Forbes (Feb. 24, 2014) available at <http://www.forbes.com/sites/paulhsieh/2014/02/24/electronic-medical-record/> (last accessed April 7, 2015).

<sup>32</sup> See 45 C.F.R. § 164.508(a)(2). HIPAA does not provide patients a right to their own psychotherapy notes. *Id.* This is particularly concerning to persons with psychiatric diagnoses as the level of errors in electronic health records is significant. See Jordan Robertson, *Digital Health Records' Risks Emerge as Deaths Blamed on System*, BLOOMBERG (June 25, 2013), <http://www.bloomberg.com/news/2013-06-25/digital-health-records-risks-emerge-as-deaths-blamed-on-systems.html> (finding doubling of reported electronic medical record errors between 2010 and 2011). See also Trevor Bertsch, Letter to the Editor, *Why We Must Keep Track of Errors in Electronic Medical Records*, SCIENTIFIC AMERICAN, Oct. 15, 2013, available at <http://www.scientificamerican.com/article/why-we-must-keep-track-of-errors-in-electronicmedical-records/> (warning of unintended consequences of electronic medical records). Pennsylvania created a mandatory reporting system for all medical errors in June 2004. This system has uncovered thousands of e-record problems—from misreported laboratory tests to incorrect prescriptions. *Id.* See also, Price *et al.*, *Assessing Accuracy of an Electronic Provincial Medication Repository*, 12 BMC Medical Informatics and Decision Making 42 (2012) (84% of pharmacist collected “best possible” medication histories has at least one error, 48% of which were deemed clinically significant). While some providers participate in pilot projects which electronically share mental health notes with patients, participation of providers is voluntary and mental health providers have the option to lock portions of their notes from patient view. Liz Kowalezyk, *Doctors' Notes on Mental Health Shared with Patients*, Boston Globe, April 8, 2014, available at <http://www.bostonglobe.com/lifestyle/health-wellness/2014/04/07/beth-israel-deaconess-mental-health-providers-share-visit-notes-with-patients/2nVs4SSYCzh2ABLeJgbCYK/story.html>. See also OPEN NOTES, [www.myopennotes.org](http://www.myopennotes.org) (last visited April 7, 2015); Kahn, *et al.*, *Let's Show Patients Their Mental Health Records*, 311 J. AMER. MED. ASSOC. 1291 (2014). Giving people greater access to their mental health records has been endorsed on the federal level as well. Health and Human Services recently published guidelines concerning patient stating that access may only be denied if it is “reasonably likely to endanger the life or physical safety of the individual or another person.” This standard ought to be “narrowly construed.” <http://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html> (last accessed Jan. 21, 2016). “General concerns” about patients’ reactions to data (e.g. they “will not be able to understand the information or may be upset”) are insufficient, as is the “mere possibility” of harm. *Id.*

<sup>33</sup> See Matthew K. Wynia & David C. Classen, *Improving Ambulatory Patient Safety: Learning from the Last Decade, Moving Ahead in the Next*, 306 J. AM. MED. ASS'N 2504, 2505 (2011). The American Medical Association report on patient safety in ambulatory care found that health care technology brings risks in addition to purported benefits, including the use of diagnostic support tools that encourage “automatic behavior” rather than careful reasoning and analysis. *Id.* “Drop-down menus of so-called best practices” fail to account for individual characteristics of patients. Milt Freudenheim, *The Ups and of Electronic Medical Records*, N.Y. TIMES, Oct. 9, 2012, at D4 (also noting the problem of cut-and-paste documentation rather than individualized patient notes). A study of the impact of IT on some Texas hospital showed some reduction in mortality, but also noted that “the lack of statistical significance among certain associations may simply indicate that clinical information technology is not a panacea for all disease conditions.” R. Amarasingham, *Clinical Information Technologies and Inpatient Outcomes*, 169 ARCH. INTERN. MED. 108, 114 (2009). ALLIAN In fact, increases in the automation of notes and records score were associated with statistically significant increases in the odds of complications for heart failure. *Id.* at 113. See also Neil Chesnow,

medical records often result in the storage of inaccurate, incomplete and outdated information,<sup>34</sup> patients must be able to retain control over providers' access to their mental health information, including psychiatric diagnoses, discharge summaries, psychiatric medication lists and psychiatrist/psychotherapist progress notes.<sup>35</sup> Indeed, given the high number of errors in records, one might question why patient consent to share is problematic, particularly if break-the-glass provisions are in place in emergencies where patient can't respond.<sup>36</sup> In addition, having a

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*Doctors Are Talking: EHRs Destroy the Patient Encounter* (May 22, 2014), available at [http://www.medscape.com/viewarticle/825369\\_3](http://www.medscape.com/viewarticle/825369_3); Sue Bowman, *Impact of Electronic Health Record Systems on Information Integrity: Quality and Safety Implications*, PERSPECTIVES IN HEALTH INFO. MGT. (Fall 2013), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3797550/>; Hsieh, *supra* note 30 (noting errors and a reduction in time spent with the patient); FOJP Service Corp., *Electronic Health Records: A Status Report*, infocus 1, 5-10 (Summer 2013) available at [http://fojp.com/sites/default/files/Infocus\\_Summer2013\\_EHR.pdf](http://fojp.com/sites/default/files/Infocus_Summer2013_EHR.pdf); Ken Terry, *Meaningful Use Not Correlated with Quality*, MEDSCAPE (April 14, 2014), <http://www.medscape.com/viewarticle/823602>. A study of clinics associated with Brigham & Women's Hospital in Boston found that, among other things, meaningful use of electronic health records resulted in worse treatment for depression. *Id.*

<sup>34</sup> Health information technology and compliance experts contend that electronic medical records are sufficiently subject to error and manipulation that they should not be used as evidence in legal proceedings without verification. B. Drury, *et al.*, *Electronic Health Records Systems: Testing the Limits of Digital Records' Reliability and Trust*, 12 AVE MARIA L. REV. 257-289 (2014).

<sup>35</sup> Alex Nixon, *Errors in Default Settings of Electronic Medical Records Systems Raise Risks for Patients*, PITTSBURGH TRIBUNE-REVIEW, Sept. 6, 2013, available at <http://triblive.com/business/headlines/4654582-74/errors-patient-patients#axzz30PH2Zldz> (reporting errors in medical records). The Pennsylvania Patient Safety Authority, a state agency that researches health care quality, found more than 300 instances of medication errors at hospitals across Pennsylvania over the last 10 years because computers did not have the correct settings. *Id.* See also James Ritchie, *Report Shows Serious Errors Resulting from Electronic Medical Records*, CINCINNATI BUSINESS JOURNAL, Apr. 8, 2013, available at <http://www.bizjournals.com/cincinnati/blog/2013/04/report-shows-serious-errors-resulting.html> (reporting results of survey). In all, the nonprofit ECRI Institute learned of 171 health care IT mix-ups that led to or could have led to harm at 36 hospitals that volunteered for the study. *Id.* The project lasted just nine weeks. *Id.* See also Richard FitzGerald, *Medication Errors: The Importance of an Accurate Drug History*, 67 BRIT. J. CLINICAL PHARMACOLOGY 671, 673 (2009) (finding inaccuracies in documentation of pharmaceutical histories in general records). A review of recent studies found 10-61% of medication lists were erroneous by omission and 13-22% had errors by commission. *Id.* Physicians and other health care providers must check those lists with patients and pharmacists for accuracy. *Id.* at 673-74. A study of records in the Veterans Health Administration's EHR system found that 84 percent of progress notes contained at least one documentation error, with an average of 7.8 documentation errors per patient. C.R. Weir, *et al.*, *Direct Text Entry in Electronic Progress Notes: An Evaluation of Input Errors*, 42 METHODS OF INFO. IN MED. 61 (2003).

<sup>36</sup> See Sarah W. Wattenberg, *Frequently Asked Questions: Applying the Substance Abuse Confidentiality Regulations to Health Information Exchange*, SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION, U.S. HEALTH AND HUMAN SERVICES 1, 13, available at <http://www.samhsa.gov/healthprivacy/docs/ehr-faqs.pdf> (describing "break the glass" provision whereby physician overrides patient consent requirement to access medical records). Such exceptional circumstances might include "the emergency room scenario" in which an unconscious patient suddenly arrives. *Id.* Where the patient is unable to communicate and has a condition that puts her life in imminent danger, the principle of patient control over the confidentiality of her medical health records is commonly overridden with a "break the glass" exception. *Id.*

conversation at the outset of treatment that includes consent to obtain mental health information will lead to more trust and open communication between doctor and patient. Patient-centered care requires just such respectful communication.<sup>37</sup> Though doctors may have an ethical duty to disclose patient information to other medical providers in some circumstances, such disclosure should only happen after an informed discussion with the patient regarding his or her preferences and concerns.<sup>38</sup> Happily, today's information technology systems can provide the levels of granularity

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Allowing anyone other than patients themselves to approve disclosure of personal medical records inherently erodes trust. By doing this, the message to patients is, in essence, "other people are going to determine who should be able to see your medical records because they understand what's in your interest better than you do." It is inherently difficult for patients to understand why, if a given disclosure is in their interest, their consent should not be obtained. Not seeking patient consent clearly leads to suspicion that the disclosure is in fact not in the interest of the patient, but rather benefits whoever is deciding that records will be shared.

William A. Yasnoff, *The Health Record Banking Model for Health Information Infrastructure*, in HEALTHCARE INFO. MGT. SYSTEMS: CASES, STRATEGIES, AND SOLUTIONS 336 (C.A. Weaver et al. eds., 2016). See Wendy Levinson, et al., *Developing Physician Communication Skills for Patient-Centered Care*, 29 HEALTH AFFAIRS 1310-18 (2010). Patient-centered care is "characterized by continuous healing relationships, shared understanding, emotional support, trust, patient enablement and activation, and informed choices. Communication skills are a fundamental component of this approach to care." *Id.* at 1311.

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Patients want to maintain control over which doctors see their sensitive information, even though a majority would share such information with their primary care physician. Kelly Caine & Rima Hanania, *Patients Want Granular Privacy Control Over Health Information in Electronic Medical Records*, 20 J. AM. MED. INFORM. ASSOC. 7 (2013). The American Medical Association recognizes patient reluctance to disclose certain medications and suggests reassuring patients that only other health care providers will be notified of the information. *The Physician's Role in Medication Reconciliation: Issues, Strategies and Safety Principles*, AM. MED. ASS'N, <http://bcpsqc.ca/documents/2012/09/AMA-The-physician%E2%80%99s-role-in-MedicationReconciliation.pdf> (last visited May 18, 2014). However, for the reasons noted above, it may be precisely these other providers that the patient is concerned about. Person-centered care requires a paradigm shift to a "culture of custodianship" of records. Talya Miron-Shatz, et al., *To Serve and Protect? Electronic Health Records Pose Challenges for Privacy, Autonomy and Person-Centered Medicine*, 1 INT'L. J. PERS. CENTERED MED. 405, 407 (2011).

. . . while health systems hold confidential information about patients, it is not the system's right to use this information as it chooses. Rather, the system needs to secure patients' consent to transfer records or data to a third party, *even if it is another medical caretaker*. One recommendation we adopt from the custodianship approach is that patients should have the ability to control the flow of their clinical data and to grant access to it.

*Id.* (emphasis added). See also *Health Record Banking Alliance Fact Sheet* <http://www.healthbanking.org/docs/HRBA%20Principles%20&%20Fact%20Sheet%202008%20FINAL.pdf> (last accessed Nov. 1, 2016). But see, Nicholas Bakalar, *Sharing Psychiatric Records Helps Care*, N.Y. TIMES, Jan. 8, 2013, at D6. The article creates the false impression that record sharing between behavioral and non-behavioral doctors leads to better patient outcomes. *Id.* Review of the underlying report does not support this premise. Among other things, the study, which was based on a very limited sample size, looked at readmissions, which other studies have questioned as a reliable indicator of quality of care. *Id.* Over a 30-day period, the length of stay was virtually identical between those facilities that shared records and those that did not. *Id.* The authors of the study itself state that further research is necessary to come to a definitive conclusion, including an analysis of the participants' race, ethnicity, and income, and that other factors not directly controlled in the study, such as social support and availability

required to segregate psychiatric information from the rest of one's medical record.<sup>39</sup>

Doctors often cite concerns about medication interactions in justifying unrestricted access to medical records.<sup>40</sup> Prescribers therefore want access to their patients' full medication lists. Of course, the utility of these lists is questionable given their error rates.<sup>41</sup> Even if one concedes the need for this information, use of existing databases that flag the possibility of such interactions obviate the need to see the full medication list to check for conflicts.<sup>42</sup> Now, as electronic medical record systems are being modified to accommodate capitated payment programs and associated quality

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of local follow-up care, which may affect readmission rates. *Id.*

<sup>39</sup> MENTAL HEALTH LEGAL ADVISORS COMM., *Consumer Control of Mental Health Information*, 5-6 (Feb. 4, 2013), available at <http://www.power2u.org/downloads/EHR-Privacy-White-Paper-2.4.13.pdf>.

For our purposes, the term "granularity" means "the extent to which smaller elements of a larger dataset may be retrieved or withheld without accessing other information from an individual record or the larger data set" . . . . The technology already exists to permit varying levels of access to information in electronic medical records. Indivo and Microsoft Health Vault are just a few examples of programs with this capacity.

*Id.* at 6. "In the past, patients exercised some degree of granularity by just going outside an insurer's network to avoid the stigma of mental illness or the sharing of "embarrassing" test results." *Id.* at 6 n.20. See, e.g., Adida, et al., *Indivo X: Developing a Fully Substitutable Personally Controlled Health Record Platform*, AMIA Symposium Proceedings, 9 (2010) [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3041305/pdf/amia-2010\\_sympproc\\_0006.pdf](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3041305/pdf/amia-2010_sympproc_0006.pdf) (last visited May 18, 2014). The symposium paper details various features of the health record platform, including access authorization and ability to customize the application with relative ease. Programs also allow records to be audited to track unauthorized access to behavioral health information. HEALTHVAULT, <http://www.microsoft.com/en-us/healthvault/> (last visited May 18, 2014). "It's your HealthVault account. You decide who can see, use, add, and share info, and which health apps have access to it." *Id.* The technical capacity exists to give patients control over which providers see their records. See, e.g., Melissa Chase, *Multi-Authority Attribute Based Encryption*, in *THEORY OF CRYPTOGRAPHY* 515-534 (Vadhan ed. 2007); Arpana Mahajan & Yask Patel, *Enhancing PHR Services in Cloud Computing: Patient-centric and Fine Grained Data Access Using ABE*, 2 INT'L J. COMPUTER SCI. INFORMATION TECH. & SECURITY 1130 (Dec. 2012). Another option is to create community "health record banks" that are independent organizations that provide a secure electronic repository for storing an individual's medical records from multiple sources and over which the individual has complete control over who accesses what information. William A. Yasnoff, *The Health Record Banking Model for Health Information Infrastructure*, in *HEALTHCARE INFO. MGT. SYSTEMS: CASES, STRATEGIES, AND SOLUTIONS* 342 (C.A. Weaver et al. eds., 2016).

<sup>40</sup> See e.g. Benjamin Grasso, *Reducing Errors in Discharge Medication Lists by Using Personal Digital Assistants*, 53 PSYCHIATR. SERV. 1325 (2002). See Nir Menachemi and Taleah H. Collum, *Benefits and Drawbacks of Electronic Health Record Systems*, 4 RISK MGMT. & HEALTHCARE POL'Y 47, 48 (2011) (noting electronic health records can reduce medication errors).

<sup>41</sup> See *supra* notes 32-35 and accompanying text (detailing the likelihood of errors contained in electronic health records).

<sup>42</sup> See *infra* note 42 (showing websites that can be used to check for conflicts).

requirements, is the time to incorporate software that provides a warning message to any provider when she types in the medication she wishes to prescribe or fill. There are many common software programs that can currently check for drug interactions by typing in the patient's name and the medication to be prescribed.<sup>43</sup>

More importantly, a computerized warning would compel the doctor to check in with her patient. That conversation could begin as follows: "I see that there is information here that I am not privy to, and while that is your choice, this is why I feel that I need this information today in order to help you make the best treatment decisions." This would require providers to ask their patients for consent when they feel access to mental health information is necessary for optimal treatment, providing an important opportunity for discussion between the provider and patient – with the provider explaining why consent would benefit the patient and the consumer using the opportunity to express her privacy concerns as they relate to her treatment.

To protect the confidentiality of mental health records, separate signed releases should be required from any health care providers wishing to access a person's mental health information, with few exceptions.<sup>44</sup> Persons with psychiatric histories are all too familiar with the repercussions

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<sup>43</sup> See, e.g., [DRUGS.COM, Drug Interactions, http://www.drugs.com/drug\\_interactions.php](http://www.drugs.com/drug_interactions.php) (last visited May 18, 2014). Walgreens pharmacy also has a database to check for drug interactions that consumers can use on its website. WALGREENS, *Check Drug Interactions*, <https://www.walgreens.com/pharmacy/library/checkdrug/selectfirstdrug.jsp> (last visited May 18, 2014). More inventive technology exists to check for potential drug interactions and return a warning without accessing a patient's full medical history as well. See, e.g., U.S. Patent No. 8229765 B2 (filed Apr. 23, 2009) (detailing patent for automatically assessing drug interactions while protecting patient privacy).

<sup>44</sup> In Australia, the government has established a personally controlled electronic health record that allows patients to specify who may access their information and specify which documents each provider may see.

You can control who accesses the information in your My Health Record. Access controls that are available include:

- Setting a record access code (a code you give to your healthcare providers to allow them to view your record, and prevent other healthcare providers from access unless in an emergency)
  - Flagging specific documents in your record as 'limited access', and controlling who can view these documents
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of being told that physical ailments are “all in the head,” from a diagnosis of anxiety when presenting with the rapid breathing of anaphylactic shock to the fatal diagnosis of depression when presenting with the fatigue of congestive heart. Persons with psychiatric histories and their advocates should be closely involved in developing privacy policies. While we look forward to a day when stigma against persons with psychiatric challenges disappears, just as affirmative action laws were (and are) necessary to combat existing racial and gender discrimination, the physical health of persons with psychiatric challenges must be protected by statutory and regulatory assurances that their psychiatric information will not be shared without their consent.

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Authorised representatives and full access nominated representatives also have the ability to change the access controls of your My Health Record. Only your healthcare provider has the ability to upload clinical information into your My Health Record. There is also a section of private notes that is only accessible to you or an authorised or nominated representative.

<https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/privacy?OpenDocument&cat=Access%20and%20Invitation%20Codes> (last accessed Oct. 25, 2016). Formerly, any document could be hidden, but now, once the patient gives access to a provider, the patient is unable to hide certain documents, including medication lists and a summary of health issues. The patient’s only option is to opt-out of the system or deny the provider any access to the record. Review of the Personally Controlled Electronic Health Record, Addendum 2 at 54 (2013). (2014), available at [https://health.gov.au/internet/main/publishing.nsf/Content/17BF043A41D470A9CA257E13000C9322/\\$File/FINAL-Review-of-PCEHR-December-2013.pdf](https://health.gov.au/internet/main/publishing.nsf/Content/17BF043A41D470A9CA257E13000C9322/$File/FINAL-Review-of-PCEHR-December-2013.pdf) (last accessed Oct. 25, 2016).