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## Consumer Control of Mental Health Information

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### Importance of consumer control

Consumers' control of the release of their mental health information is critical to ensuring their right to privacy. Stigma about mental illnesses remains pervasive and can affect many aspects of people's lives, including employment, family relationships, legal rights, and access to appropriate medical and mental health care.<sup>1</sup> The following will detail the rationale and supporting research for the recommendation that specific authorization, beyond that mandated by current law,<sup>2</sup> be required to access anyone's mental health information, with few exceptions.<sup>3</sup>

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<sup>1</sup> See S. Rosenfield, *Labeling Mental Illness: The Effects of Received Services and Perceived Stigma on Life + Satisfaction*, 62 *American Sociological Review* 660 (Aug. 1997).

<sup>2</sup> For current law, see, e.g., Mass Gen. Laws ch. 112 §§ 129A (psychologists), 135A (social workers), 172 (allied mental health professionals), Mass Gen. Laws ch. 175 § 108E (insurance companies), Mass Gen. Laws ch. 111 § 70E (hospitals), and Mass Gen. Laws ch. 123 §36 (Department of Mental Health). It should be noted that HIPAA, the Privacy Rule, 45 CFR Part 160 and Part 164, Subparts A and E, permits the disclosure to any person providing health care to a patient, *without the patient's authorization*, of the following mental health information, which is excluded from the definition of psychotherapy notes:

- medication prescription and monitoring,
- counseling session start and stop times,
- modalities and frequencies of treatment furnished,
- results of clinical tests, and
- any summary of the following items: diagnosis, functional status, treatment plan, symptoms, prognosis, and progress to date.

45 C.F.R. § 164.501.

<sup>3</sup> Mass Gen. Laws ch. 112, § 129A, while limiting disclosure of information by a psychologist, provides a

Consumers are justifiably concerned about protecting the privacy of their psychiatric information<sup>4</sup> because of the potentially dire consequences that they face when such information becomes known.<sup>5</sup> 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.<sup>6</sup> Indeed, the imposing stigma still associated with mental illness often prevents people from seeking appropriate behavioral health care.<sup>7</sup> If people were more confident that their information would not be shared beyond those with whom they desired, people might be less reticent to access mental health care.<sup>8</sup>

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public safety exception which allows release of certain treatment information where the patient poses “a clear and present danger to himself or a third party.” Such releases should be limited in scope to what is necessary to prevent the harm. One might look to 251 CMR 1.11, under which a psychologist, if releasing information as part of a consultation, must use her best efforts to safeguard the patient’s privacy by not disclosing his name or any information that could identify him. When a patient comes to see a therapist specifically to get a psychological evaluation for a third party, such as a court, the patient must be informed about all confidentiality limitations before said evaluation begins. Lastly, Massachusetts law authorizes a limited release of information about a patient’s treatment to process, approve or audit insurance benefits. Mass. Gen. Laws ch. 112, § 129A.

<sup>4</sup> See, Breaches Affecting 500 or More Individuals, U.S. Department of Health and Human Services, Health Information Privacy, <http://www.hhs.gov/ocr/privacy/hipaa/administrative/breachnotificationrule/breachtool.html> (last accessed December 17, 2012) (reporting over 250,000 persons affected by privacy breaches in 2012 alone). The more persons with whom information is shared, the greater the likelihood of unauthorized releases of private information.

<sup>5</sup> See O. Wahl, *Mental Health Consumers’ Experience of Stigma*, 25 Schizophrenia Bulletin 467 (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.”) 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 (HIV/AIDS test results); Mass. Gen. Laws ch. 111 § 70G (genetic testing); and 105 CMR 127.020 (D) (mammograms).

<sup>6</sup> See R. Salomon, *Openness of patients’ reporting with use of electronic records: psychiatric clinicians’ views*, 17 Journal of the American Medical Informatics Assoc. 54-60 (2010).

<sup>7</sup> P. Corrigan, *How Stigma Interferes with Mental Health Care*, 59 American Psychologist 614, 621 (Oct. 2004) (noting that many people who would benefit from mental health services fail to seek or fully participate in such services because of stigma, “namely, to avoid the label of mental illness and the harm it brings,” and because of concerns about confidentiality of psychiatric information).

<sup>8</sup> E. Golberstein, et al., *Perceived Stigma and Mental Health Care Seeking*, 59 Psych. Services 392, 398 (2008) (in study finding no association between perception of stigma and care seeking in students at a Midwestern university, authors posited that one “explanation is that many respondents had confidence

Prior to accessing mental health information, it is incumbent upon treating clinicians to have detailed conversations with their patients to obtain informed consent to treatment. Having a 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>9</sup>

Disclosure of psychiatric information not only discourages some people from seeking mental health care, it also can prevent persons with mental health issues from accessing or receiving appropriate medical health care for their physical ailments.<sup>10</sup> One survey of 300 family physicians determined that “past psychiatric history influences physicians’ estimation of disease presence and willingness to order tests.”<sup>11</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>12</sup> One article notes people with mental illness:

reported professionals as being dismissive or assuming that physical presentations were “all in the mind” (Lyons et al, 2009). 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

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that their service use would remain confidential and could thus avoid the consequences of being labeled as having a mental disorder.”)

<sup>9</sup> See W. 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.” (citations omitted)).

<sup>10</sup> See e.g., G. Thornicroft, *Discrimination in health care against people with mental illness*, 19 *International Review of 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)); M. Heron, et al., *Deaths: Final data for 2006*, 57 *National Vital Statistics Reports*, No. 14 (National Center for Health Statistics, April 2009) (Life expectancy for people with major mental illness is 56 years while the “average” American life expectancy is 78 years).

<sup>11</sup> M. Graber, et al., *Effect of a Patient’s Psychiatric History on Physicians’ Estimation of Probability of Disease*, 15 *J. Gen. Internal Med.* 204 (2000).

<sup>12</sup> See e.g., E. Koranyi, *Morbidity and Rate of Undiagnosed Physical Illnesses in a Psychiatric Clinic Population*, 36 *Arch. Gen. Psychiatry* 414-419 (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.). See also, O. Wahl, *Mental Health Consumers’ Experience of Stigma*, 25 *Schizophrenia Bulletin* 467, 473 (1999) (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.”)

greater risk from physical health problems, including cardiovascular disease, diabetes, obesity and respiratory disease ....<sup>13</sup>

Reports from people with psychiatric histories on their experiences with health care providers range from ordinary rudeness to refusal to treat serious medical conditions ultimately confirmed as real.<sup>14</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. And more than half of these physical conditions either caused or greatly exacerbated these patients' psychiatric conditions.<sup>15</sup> Another 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>16</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

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<sup>13</sup> See S. Parle, *How does discrimination affect people with mental illness?* 108 *Nursing Times* 28:12-14 (2012).

<sup>14</sup> P. Byrne, *Stigma of mental illness and ways of diminishing it*, 6 *Advances in Psychiatric Treatment* 65-72 (2000) ("Any list of stigmatizers must include...health care professionals..."). Byrnes 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. Provider misconceptions about people with psychiatric histories contribute to low quality physical health care for persons with psychiatric histories.

<sup>15</sup> 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. 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. 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.)

<sup>16</sup> A recent article, "*Sharing Psychiatric Records Helps Care*, *New York Times* at D6 (Jan. 8, 2013), creates the false impression that record sharing between behavioral and non-behavioral doctors leads to better patient outcomes. 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. Over a 30-day period, the length of stay was virtually identical between those facilities that shared records and those that did not. 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 of local follow-up care, may affect readmission rates.

and treatment they need, or if, in some cases, their physical symptoms are misattributed to their mental illness.<sup>17</sup>

Further, undue disclosure of psychiatric information can lead to negative public health consequences, including the avoidance of necessary care 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 test altogether. If we do not restore patient control over PHI, 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 reached with such a high rate of errors and omissions.<sup>18</sup>

Because of these issues, it is very important that patients retain control over providers' access to their mental health information, including psychiatric diagnoses, discharge summaries, psychiatric medication lists and psychiatrist/psychotherapist progress notes.

### **The Information Technology**

We currently have the knowledge and technical ability to:

- Separate information
- Control access to information
- Collect medication lists
- Check for medication conflicts, and
- Return information to the requesting party without disclosing all underlying data used to produce the response.

We therefore have the technical ability to provide consumer control over mental health information.

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<sup>17</sup> Reeves, et al., *Unrecognized physical illness prompting psychiatric admission*, 22 *Annals of Clinical Psychiatry* 180, 184 (2010) (concluding medical symptoms of patients with a history of mental illness are more likely to be attributed to psychiatric illness than are comparable symptoms in patients without such a history).

<sup>18</sup> Consumer Action, *Ensure "meaningful use" by giving consumers control* (June 2009), [http://www.privacy-information.org/articles/ensure\\_meaningful\\_use\\_by\\_giving\\_consumers\\_control\\_over\\_their\\_health\\_infor\\_ma](http://www.privacy-information.org/articles/ensure_meaningful_use_by_giving_consumers_control_over_their_health_infor_ma) (last accessed December 13, 2012)

## Granularity

Today's information technology systems can provide the levels of granularity required to segregate psychiatric information from the rest of one's medical record. 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." Almost without exception, the individual patient should control the level to which all mental health related information, including diagnoses, treatment and psychiatric medications, are shared with other health care providers.<sup>19</sup>

The technology already exists to permit varying levels of access to information in electronic medical records.<sup>20, 21</sup> Indivo and Microsoft Health Vault are just a few examples of programs with this capacity.<sup>22</sup> Programs also allow records to be audited to track unauthorized access to behavioral health information.<sup>23</sup>

We understand that doctors may have an ethical duty to disclose patient information to other medical providers in some circumstances.<sup>24</sup> Yet, such disclosure should only happen after an informed discussion with the patient that takes the patient's preferences and concerns into account.<sup>25</sup>

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<sup>19</sup> Such exceptional circumstances might include "the emergency room scenario" in which an unconscious patient suddenly arrives. 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.

<sup>20</sup> 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.

<sup>21</sup> Additional encryption and control over access to all medical records is warranted. Patients have a solid basis for fearing that information about their mental health condition will be too widely shared. *Digital Data on Patients Raises Risk of Breaches*, New York Times (Dec. 18, 2011).

<sup>22</sup> See [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 accessed 11/21/12) and <http://www.microsoft.com/en-us/healthvault/> (last accessed 12/24/12), respectively.

<sup>23</sup> See, e.g., Adida, et al., *Indivo X: Developing a Fully Substitutable Personally Controlled Health Record Platform*, AMIA 2010 Symposium Proceedings 6-10, at 9.

<sup>24</sup> See "The physician's role in medication reconciliation: Issues, Strategies and Safety Principles," <http://www.ama-assn.org/resources/doc/cqi/med-rec-monograph.pdf> (last accessed 11/30/2012) (recognizing patient reluctance to disclose certain medications and suggesting that reassuring patients that only other health care providers will be notified of the information). However, for the reasons noted above, it may be precisely these other providers that the patient is concerned about.

<sup>25</sup> Person-centered care requires a paradigm shift to a "culture of custodianship" of records.

### Medication interactions

We understand that doctors are concerned about medication interactions and therefore want access to their patients' full medication lists. Using existing databases that flag the possibility of such interactions, such access is not necessarily a prerequisite to reconciling medications.

As electronic medical record systems are modified to accommodate capitated payment programs and associated quality requirements, now 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. For example, Walgreens pharmacy has a database to check for drug interactions that consumers can use on its website.<sup>26</sup> In other words, the technology already exists to check for potential drug interactions and return a warning without accessing a patient's full medical history, and instead, using a stored list of her medications. It should be a relatively simple IT process to ensure that a system can check for drug interactions and return a warning using a stored and confidential list of the patient's medication without actually giving the doctor a list of those medications. Any warning message related to a possible interaction could also provide a range of alternative medications that would not negatively interact with the patient's current medications.<sup>27</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."

Thus, providers would be required to ask their patients for consent when they felt access to mental health information was necessary for optimal treatment. This would provide 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.

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...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 that 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.

T. Miron-Shatz, et al., *To serve and protect? Electronic health records pose challenges for privacy, autonomy and person-centered medicine*, 1 International Journal of Person Centered Medicine 405, 407 (2011). (emphasis added).

<sup>26</sup> See <https://www.walgreens.com/pharmacy/library/checkdrug/selectfirstdrug.jsp> (last accessed 11/30/12); see also, [http://www.drugs.com/drug\\_interactions.php](http://www.drugs.com/drug_interactions.php) (last accessed 12/13/12).

<sup>27</sup> Off-the-shelf products provide alternative medication suggestions. See <http://www.epocrates.com/products/online/premium> (last accessed 12/13/12).

## **Conclusion**

To protect the confidentiality of mental health records, we recommend that separate signed releases be immediately required from anyone, including health care providers, to access a person's mental health information, with few exceptions. Persons with psychiatric histories are all too familiar with the repercussions of being told that physical ailments are "all in the head," from delayed diagnoses of mononucleosis, lupus, and a viral infection causing balance problems to near-fatal misdiagnoses of congestive heart failure and anaphylaxis. Therefore, we also recommend that persons with psychiatric histories and their advocates be closely involved in developing privacy policies. We look forward to working with other stakeholders and their representatives on the more specific issues involved in the implementation of consumer control of mental health information.

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