

MENTAL HEALTH LEGAL ADVISORS COMMITTEE

Commonwealth of Massachusetts
Supreme Judicial Court



MaMHCA

Massachusetts Mental Health
Counselors Association, Inc.

Testimony of Mental Health Legal Advisors Committee and Massachusetts Mental Health Counselors Association for the 2018 Health Care Cost Trend Hearing

This testimony is submitted on behalf of Mental Health Legal Advisors Committee (MHLAC) and the Massachusetts Mental Health Counselors Association (MaMHCA). MHLAC is an agency under the Massachusetts Supreme Judicial Court that provides representation to low-income persons with psychiatric challenges. MHLAC also provides information and advice to any Commonwealth resident, including the legislature, other agencies and commissions on mental health legal matters. MHLAC presented oral testimony at the October 16, 2018 Cost Trend Hearing. MaMHCA is dedicated to providing essential professional information and ongoing education and training to Licensed Mental Health Counselors, mental health counseling students and educators, and other related professionals. MaMHCA advocates for the advancement of the high quality mental health services and the mental health counseling profession through public policy initiatives for both mental health professionals and consumers of mental health services.

In considering health cost trends and an appropriate benchmark for growth in healthcare costs, the Health Policy Commission (HPC) looks at potential drivers of costs as well as practices that will reduce healthcare expenditures. MHLAC and MMHCA direct their comments to these factors. Key points addressed below are:

- **Financial incentives** to reduce costs, such as capitation and pay for performance, often have unintended results¹ and should not be pursued without careful scrutiny

¹ For a fuller discussion of the unintended results of alternative payment arrangements than is contained in these comments, please contact MHLAC for its White Paper, "The Unintended Results of Payment Reform."

and transparency. Outcome measurements do not sufficiently modify financial incentives to ensure quality of care. **Shifting costs to insureds** is not based on person-centered or evidence-based criteria, disregards the quality of care rendered to individual, and hurts low- and moderate-income patients.

- **Innovative approaches to health care**, including addressing social determinants of health, are not typically covered by insurance or included in traditional medical models of care yet are fundamental to reducing health care costs.
- **Health care delivery systems**, like integrated care, should not be assumed to be beneficial for all persons or to result in decreased health care expenditures.²
- **Administrative costs** of private insurance should be included in the examination of health care cost drivers.

Financial Incentives

Health care costs obviously can be reduced if insurers deny coverage for medically necessary services or providers refuse to recommend it. In the 1990s, health maintenance organizations were faulted for doing just this.³ Of course, the HPC has no interest in reducing costs by reducing quality of care. It should therefore carefully scrutinize financial incentives to cut care.⁴ Engaging front-line health care providers in cost-cutting

² D. Cooper, *et al.*, *Association Between Mental Health Staffing Level and Primary Care-Mental Health Integration Level on Provision of Depression Care in Veteran's Affairs Medical Facilities*, 45 Adm. Policy Mental Health 131 (2018)(finding level of integration of primary care and mental health did not significantly affect likelihood of adequate psychotherapy for patients with either new or chronic depression or adequacy of antidepressant treatment); E. Stuart, *et al.*, *Effects of accountable care and payment reform on substance use disorder treatment: evidence from the initial 3 years of the alternative quality contract*, 112 *Addiction* 124 (2017)(finding accountable care model did not lead to substantial changes in use of substance use disorder services).

³ See, e.g., Jacqueline Kosecoff *et al.*, *Prospective Payment System and Impairment at Discharge: The "Quicker-and-Sicker" Story Revisited*, 264 J. AM. MED. ASS'N 1980 (1990). In a study with a sample size of over 10,000 patients, in which the hospitals were paid a fixed amount per patient rather than being reimbursed based on the patient's actual cost of care, the patients were repeatedly discharged sooner and in less stable condition. *Id.* "[O]ne (17%) of six patients was discharged with at least one instability, two (39%) of five patients . . . [had] at least one measure of sickness, and one (24%) of four patients had an abnormal last laboratory [test result]." *Id.* at 1980-81.

⁴ See, e.g., B. Kaufman, *et al.*, *Impact of Accountable Care Organizations on Utilization, Care, and Outcomes: A Systematic Review*, *Med. Care Research and Rev.* 1, 16 (Nov. 2017)("The evidence for the effect of ACOs on care processes and outcomes is mixed...."); H. Hennig-Schmidt, *et al.*, *How payment systems affect physicians' provision behavior – An experimental investigation*, 30 J. Health Eco. 637

efforts through financial incentives are very likely to result in a return to the experience of health maintenance organizations in the 1990s.⁵

Outcome measurements will not fully address the negative impact of financial incentives.

Unfortunately, most measures of quality, such as hospital readmission rates, are crude. We cannot depend upon commonly-used outcome measurements, such as reduced hospital admissions, to guarantee quality of care.⁶

Even quality-related financial incentives can have ironic results. For example, **pay for performance** usually results in some improvement, at least temporarily, in the practices for which payment is made. However, studies show that those items not measured or incentivized often experience a decrease in the quality of care, sometimes resulting in an overall reduction in care quality.⁷

(2011) (Physicians provide 33% fewer services under capitation than under fee-for-service. Patients in intermediate or bad health suffer a larger benefit loss under capitation than those in good health.)

⁵ See Hennig-Schmidt, *supra* n. 3. Physicians were given the exact same scenarios that varied only by the financial incentives to the physician. Where the provider's remuneration would be reduced by providing services, the providers recommended about a third fewer services. Managed care provided cost-cutting incentives to the detriment of patients. These findings strongly suggest that bringing front line health care workers into cost-cutting efforts will alter their recommendations and damage care, not to mention public trust in the health care system.

⁶ Hospital readmission rates can be kept low simply by denying readmission or coverage of readmission. Furthermore, certain mental health conditions do not necessarily result in admissions or readmission. An individual with such conditions may instead become homebound, homeless or incarcerated.

When financial consequences are linked to the outcome, unintended effects could occur. For example, hospitals may try to reduce their readmission to escape the penalty of exceeding the readmission rate by lowering admissions, moving readmissions after the 30-day window, or risk avoidance in regards to high risk groups. These gaming efforts might reduce the focus on the actual intention: improving quality of hospital care.

C. Fischer, *et al.*, *Is the Readmission Rate a Valid Quality Indicator? A Review of the Evidence*, 9 PLOS ONE e112282. doi:10.1371/journal.pone.0112282 (2014)(unrelated correction Feb. 2015: <https://doi.org/10.1371/journal.pone.0118968>).

⁷ One study of pay for performance with primary care providers in England found that while the payments accelerated improvements in quality for two of the three chronic conditions targeted, the rate of improvement slowed and the quality of those aspects of care not associated with the incentive actually declined. Campbell *et al.*, *Effects of Pay for Performance on the Quality of Primary Care in England*, 361 New Eng. J. Med. 368 (2009). In addition, pay for performance is often instituted at a point in time where the practice being incentivized is already being adopted without any bonus payment.

The common presumption that a focus on value as well as cost efficiencies will promote better care is also flawed.

The problem with “value-based” care is that it usually represents the priorities of the payers and providers, not the recipients of care. As with pay for performance, the measurements of value are decided without seeking or giving due regard to input from patients or those engaged in health care advocacy⁸ on patients’ behalf.⁹

Failing to adequately consider patient input will tend to result in the valuing of insurer and payer- preferred treatments without adequate consideration of **social costs**. For example, the failure to solicit patient preferences in lieu of medication could result in an inappropriately high valuing and use of pharmaceutical mental health interventions. Undue emphasis on such treatment will also negatively affect quality of care because at least some patients strongly affected by medication side effects will eschew treatment entirely.

Social costs are linked to economic costs. Untreated patients will tend to generate higher and avoidable acute care costs. They will less often maintain steady employment and more often become reliant on public programs. Limiting recovery options also increases criminal justice costs when behavior results in arrest, court-processing, and imprisonment. By contrast, research shows that health care systems offering a wide array of treatment options appealing to a greater number of patients with varying preferences reduce costs and improve outcomes.¹⁰

⁸ The patient representatives on some ACO boards do not represent typical members and their interests. For example, the representative is spectacularly wealthy or was a former health care executive. Patient input should come from persons representative of patients or whose work has been dedicated to patient advocacy.

⁹ MHLAC lauds the HPC in its move toward using patient reported outcome measures for ACO certification. However, even PROMS will not reflect patient perspectives on quality of care if the wrong questions are asked. The need for true patient advocates to have a seat at the table remains after a system of outcome measurements is chosen.

¹⁰ J. Swift and J. Callahan, *The impact of client treatment preferences on outcome: a meta-analysis*, 65 J. Clinical Psychology 368-381(2009); O. Lindhiem, *et al.*, *Client preferences affect treatment satisfaction, completion, and clinical outcome: A meta-analysis*, 34 Clin. Psych. Rev. 506 (2014); Q. Le, *et al.*, *Effects of treatment, choice, and preference on health-related quality-of-life outcomes in patients with posttraumatic stress disorder (PTSD)*, Qual. Life Res. (2018)(<https://doi.org/10.1007/s11136-018-1833-4>); R. Williams, *et al.*, *Patient preference in psychological treatment and associations with self-reported outcome: national cross-sectional survey in England and Wales*, BMC Psych. 4 (2016)(patients who had preferences for type of therapy and were not offered adequate choice were around six times less likely to agree that they had been helped by the treatment than those who were offered their choice).

Bundled payments for episodes of care are anathema to person-centered, let alone person-driven care. Just as computer-generated treatment recommendations cannot be applied without modifying them for an individual's preferences, as well as the individual's complete medical and social circumstances, neither can rigid bundled payments promote long-run cost savings or quality when services are so dependent on these factors.

Patient Reported Outcome Measures (PROMS) are a move in the right direction, measuring the value of services from the patient perspective.¹¹ Health outcomes should not be defined just as clinical outcomes or in terms of cost-efficiency, but, instead, ought to encompass holistic analysis of individual well-being. "Improving health includes broader aims, such as tackling the social determinants of health, allowing people the 'freedom to lead lives they have reason to value.'"¹²

As discussed below, offering a broader array of services, including those that are innovative and address social determinants of health, are necessary to produce the consumer engagement that will lead to better overall outcomes.

Counter-productive cost shifting.

Shifting costs to consumers is ineffective in both the short and long term. For example, **tiering** of providers is ineffective. People do not shop for healthcare like they shop for appliances; much more is at stake and the need for the service is often immediate. This precludes leisurely shopping. A patient in this position is not emotionally or physically able to undertake the complex research necessary to render well-founded choices between providers. This is particularly true when fundamental information, such as the financial incentives under which the healthcare provider operates, is not provided to patients.

Additionally, tiering of providers ignores the inability of patients who have special needs to exercise genuine choice due to an inadequate supply of providers (e.g. same gender providers for women traumatized by sexual assault; limited English proficient providers).

¹¹ S. Gentry and P. Badrinath, *Defining Health in the Era of Value-based Care: Lessons from England of Relevance to Other Health Systems*, 9 Cureous 2017 at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5383371/> (last accessed 3/8/18) ("One example of a move toward value-based outcome assessment in the English NHS is Patient Reported Outcome Measures....").

¹² S. Gentry and P. Badrinath, *Defining Health in the Era of Value-based Care: Lessons from England of Relevance to Other Health Systems*, 9 Cureous 2017 at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5383371/> (last accessed 3/8/18). The World Health Organization defines health as 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity'.

If appropriate providers are in higher cost tiers, such patients will be forced to incur high co-payments to get what they minimally need and/or they may wait inordinately long times for appointments with appropriate lower-tier providers who are in short supply (e.g. bi-lingual providers).

Tiering systems are not transparent nor are they consistently resulting in “value.”¹³ Increasing cost-sharing differentials between tiers simply hurts low and moderate income persons. One study concluded that there was no significant change of the utilization of medications for which co-pays were increased, but that there was shifting of costs from insurers to consumers.¹⁴ For all these reasons, tiering is a pretext for transferring costs to patients to benefit insurers and ACOs, not to increase quality of care.

No matter how **co-pays or deductibles are increased**, it can result in avoidance of medically necessary care or “non-compliance” with physician recommendations.¹⁵ For instance, some elderly cut their medications in half to make them last longer. The ultimate result of increasing member costs is not higher quality care, rather it is greater poverty and low and moderate-income people ending up in the hospital or with more serious illnesses that require treatment, thus *increasing* morbidity, mortality, and costs.

MHLAC is opposed to increasing premium costs to employees who choose plans not designated as “high-value” plans. Many of these plans have very limited networks. Due

¹³ A. Ryan, *et al.*, *Linking Spending and Quality Indicators to Measure Value and Efficiency in Health Care*, 74 Med. Care Research and Rev. 452 (2017) (relative merits of alternative approaches that combine quality and spending indicators are not well understood; seven alternative tiering models in use or that have been proposed resulted in widely varying results). The authors state that the drive to tier providers by cost and quality “has outpaced scientific consensus about how best to incorporate these measures into accountability efforts.” *Id.* at 454. Particularly in light of insurers’ demands that covered treatments be evidence-based, advocacy for tiering without evidentiary support for anything other than reduced costs to payers is unjustified.

¹⁴ K. Yeung, *Impact of a Value-Based Formulary on Medication Utilization, Health Services Utilization, and Expenditure*, 55 Med. Care 191 (2017). The only change in utilization was for lower tier preventive medications for which co-pays were decreased. Member medication expenses increased by 9%, while health plan medication expenses decreased by 16%. This shift of wealth is troubling, particularly in light of Dr. Ashish Ja’s presentation at the Oct. 16, 2018 HPC Annual Health Care Cost Trends Hearing, which pointed to the extremely high portion of the income of low- middle and moderate income persons that is spent on medical care (23-32%).

¹⁵ See, J. Piette, *et al.*, *Cost-Related Medication Underuse Among Chronically Ill Adults*, 94 Am. J. Pub. Health 1782 (2004); B. Briesacher, *et al.*, *Patients at Risk for Cost-Related Medication Nonadherence*, 22 J. Gen. Intern. Med. 864 (2007) (Up to 32% of elderly take less medication than prescribed to avoid costs). Research has established consistent links between medication nonadherence due to costs and financial burden, and to symptoms of depression and heavy disease burden.)

to the limited selection of providers in these networks, insureds are forced to choose between existing providers or abandon their existing providers altogether.

If, as the HPC proposes, employers incentivize workers to choose “high-value” plans by paying the same about toward insurance premiums regardless of the cost of the plan, low-wage and moderate income workers are put between a rock and a hard place. If the worker cannot afford the plan with his or her providers, this incentive scheme will interrupt **continuity of care**, which is detrimental to care and to costs. Plan limits on the time to transition to new providers, if any time, are inadequate. From the point of view of both the insurer and the insured,¹⁶ it makes no sense to require someone to transition from a provider with whom they have a successful working relationship. Such a cut-off risks re-traumatization of persons with psychiatric challenges and decompensation. Indeed, there is no reason to disrupt any solid working relationship and, for mental health treatment, definite reasons not to breach a developed therapeutic alliance. The therapeutic relationship is the single most accurate predictor of successful outcome of treatment.¹⁷ Single-case out-of-network agreements should be available for an unlimited time period to providers who are willing to abide by a plan’s reasonable administrative and care coordination requirements.

¹⁶While not providing a totally unlimited ability to choose one’s mental health provider, England has recognized the value of provider choice to both the patient and the health care system. Indeed, a guidance states: “We’re aware of some ... policies that require the use of local providers either exclusively or for all initial referrals. These policies may prevent people from choosing the provider of care that is best for them; they aren’t appropriate.” NHS Improvement, *Choice in mental health: advice for commissioners* at 2 (April 2016), https://improvement.nhs.uk/documents/59/choice_in_mh_services_commissioners_2.pdf (last accessed Oct. 11, 2018).

Health care plans can use information about the choices people make to improve services. If more people are choosing to go to a particular out-of-network provider or provider group, the insurer could contract with that provider or group. The insurer could also consider contracting or establishing clinics to fill service gaps identified. *See id.*

¹⁷ J. Safran, et al., *Alliance, Negotiation and Rupture Resolution*, in Handbook of Evidence Based Psychodynamic Therapy, at 208 (2009) (the quality of the patient-therapist relationship is more important than the treatment modality). *See also*, J. Sharf, et al., *Dropout and Therapeutic Alliance: a Meta-Analysis of Adult Individual Psychotherapy*, 47 Psychotherapy Theory, Research, Practice, Training, 637-645 (2010). *See also*, B. Arnou, et al., *The Relationship Between the Therapeutic Alliance and Treatment Outcome in Two Distinct Psychotherapies for Chronic Depression*, 81 J. Consulting and Clinical Psychol. 627 (2013); J. Norcross, ed., *Evidence-Based Therapy Relationships* (2011) at 8 (“Alliances with both youth and their parents are predictive of treatment outcomes.”) and at 15-16 (outcomes and patient well-being is considerably enhanced with a better collaborative relationship and goal consensus).

For these reasons, presumptions concerning alternative payment modalities and cost shifting must be monitored using more than cost-effectiveness and process measurements. Rather, actual outcomes, using patient-reported outcomes, functional assessments, and social costs, as well as clinical measures, should be tracked.

Innovative Services

Instead of relying upon alternative payment arrangements which are reminiscent of managed care of years gone by or shifting costs to consumers, innovative approaches to healthcare must supplement and replace our limited traditional approaches to illness and recovery. It is not possible to save substantially on health care while doing the "same old, same old."

Everyone's path to recovery is different. Reform of behavioral health care practices requires accepting input from the recipients of care.^{18, 19} One of the key problems with our current health care delivery system is that it fails to address individual preferences and needs.²⁰

¹⁸ Shared decision-making has been found to reduce inpatient hospitalization costs, a large driver of overall health care costs. J. Lofland, *et al.*, *Shared decision-making for biologic treatment of autoimmune disease: influence on adherence, persistence, satisfaction, and health care costs*, 11 Patient Pref. Adherence 947, 956 (2017)(patients who did not engage in shared decision-making had inpatient hospitalization costs 2.6 times greater than those who did).

¹⁹ D. Cooper, *et al.*, *Association Between Mental Health Staffing Level and Primary Care-Mental Health Integration Level on Provision of Depression Care in Veteran's Affairs Medical Facilities*, 45 Adm. Policy Mental Health 131, 138 (2018)("[I]t is important to identify patient preferences for care, and to ascertain how current care addresses these....").

²⁰ Person-centered care requires a broad array of treatment options. I. Kovacevic, *et al.*, *Self-care of chronic musculoskeletal pain – experiences and attitudes of patients and health care providers*, 19 BMC Musculoskeletal Disorders 76 (2018)(Patients "lack individualized care from conventional medicine.")

If a broad array of options are not available, persons may reject substance use disorder (SUD) and mental health (MH) services altogether or may turn to self-medication, ultimately increasing both health care and social costs. For example, we know that a large portion of persons who become addicted to opioids start with prescription medication for pain. A. Wilson-Poe and J. Morón, *The dynamic interaction between pain and opioid misuse*, Brit. J. of Pharmacology 1 (May 9, 2017)(nearly half of persons with chronic pain and SUD reported the SUD began with an opioid prescription for pain). Therefore, person-centered care should include, among other things, complementary and alternative treatments for pain control, which often is not covered by insurers. For example, while not producing statistically significant results, acupuncture resulted in less intra-operative and post-operative morphine equivalent usage, lower average pain scores and fewer days at home taking less opioids following gynecological surgery. E. Yoselevsky, *et al.*, *A prospective randomized, controlled, blinded trial of pre-operative acupuncture in the*

Giving adequate regard to patient preferences is a requisite to reducing costs. There are alternatives that are both cheaper and more effective. example of a service that has proven to be low cost and is preferred by many patients is peer respite. This is exactly the kind of service that is “high value, low cost” and that will prevent unnecessary hospitalizations.²¹ Peer respite offers a safe haven for people experiencing psychiatric crises. Preferably, it is run by persons who have had psychiatric challenges, i.e., peers. It also is staffed with peers. Many people with psychiatric challenges would prefer peer respite over an emergency room or a psychiatric inpatient facility.

In studies with a control or comparison group, respite guests were 70% less likely to use inpatient or emergency services and average psychiatric hospital costs were \$1,057 for respite users compared with \$3,187 for non-users.²² Investment in and use of peer respite is thus especially pertinent to the reduction of hospital utilization, first on the list of HPC’s spending reduction scenarios.²³ A study in the October 2018 issue of *Psychiatric Services* concludes:

Clients who received peer-staffed crisis respite services demonstrated lower rates of hospitalization and Medicaid expenditures in the month of and immediately following receipt of these services compared with a comparison group. The findings provide evidence that implementing peer-staffed crisis respites to divert individuals from hospitalization can achieve savings in Medicaid expenditures and reduce reliance on hospital services.²⁴

management of pain in gynecologic surgery, Am. J. Obs. & Gyn, S.890 (Feb. 2018). Mindfulness meditation also has been shown to result in enhanced pain control. A. Wilson-Poe and J. Morón, *The dynamic interaction between pain and opioid misuse*, Brit. J. of Pharmacology 1 (May 9, 2017).

²¹ Additional means to prevent hospital utilization is to provide evening and weekend office hours, without an additional co-pay for urgent care; to allow walk-in care, which has had the fortuitous effect of reducing no-shows for one clinic that implemented the policy; and to provide peer support.

²² <http://www.peerrespite.net/research/> (last accessed 3/8/18).

²³ See n. 4 for concerns about using hospital readmissions as an outcome measurement. Similar concerns exist in relation to relying on readmission denials as a means to reduce costs as the motivation behind denying a readmission may not place the patient’s best interests in the forefront.

²⁴ E. Bouchery, et al., *The Effectiveness of a Peer-Staffed Crisis Respite Program as an Alternative to Hospitalization*, 69 Psych. Serv. 1069, 1073 (Oct. 2018). The 20 to 30 peer staff in each New York City peer respite centers were supervised by three to five nonpeers. Clients are full participants in treatment decision-making. *Id.* at 1070.

Although DMH Commissioner Joan Mikula believes in the efficacy of peer respites, only one peer respite exists in Massachusetts²⁵ and, as a rule, peer respite is not covered by insurance. This is absurd as peer respite is considerably less expensive than inpatient hospitalization.

Another example relates to pharmaceuticals. Numerous parties who pre-filed testimony in anticipation of the HPC Cost Trends hearing pointed to the high cost of pharmaceuticals. Many persons with psychiatric challenges would prefer alternatives to medications that have negative side effects. Certain healthy diets reduce the severity, or prevent the onset of, mental health conditions, cognitive impairments, and even physical ailments.²⁶ Rather than forcing people to take medication that they do not want, in some cases at least, coverage of the costs of healthy foods will be less expensive in the long and perhaps even the short-run than many of the medications prescribed for psychiatric and cognitive conditions.

Service animals are another tool that could be used to reduce healthcare expenditures, including medication expenditures that the HPC report on health care expenditures notes is a significant cost driver. The former Chief Medical Director of the District of Columbia's Department of Mental Health, Colonel (Ret.) Elspeth Cameron Ritchie, M.D., attests that when persons with posttraumatic stress disorder are given service dogs, they frequently are able to successfully discontinue medication.²⁷ Again, despite the abundance of evidence supporting the efficacy of pet therapy and service animals for mental health conditions, insurers generally refuse to cover their provision.

"Housing First" is another approach that is under-utilized because it does not fit into the traditional medical model of healthcare.²⁸ It is based on the premise that the physical and mental health care needs of the homeless cannot be addressed until they are provided a home. Instead of requiring sobriety or compliance with medication to obtain an apartment, the homeless individual is provided a place to live and must only abide by the

²⁵ "Afiya is located in a residential neighborhood in Northampton, Massachusetts and is central to a variety of community resources. It is available to anyone ages 18 and older who is experiencing distress and feels they would benefit from being in a short-term, 24-hour peer-supported environment with others who have 'been there.' Typical stays at Afiya range from one to seven days."
<http://www.westernmassrlc.org/afiya> (last accessed 3/8/2017).

²⁶See F. Jacka, *et al.*, *Food policies for physical and mental health*, 14 BMC Psych. 132 (2014).

²⁷ Presentation of Col. (Ret.) Ritchie, M.D. at MHLAC training held Nov. 15, 2016, Massachusetts Continuing Legal Education, Boston, MA.

²⁸ Local pilots exist in Massachusetts. See, Boston Public Health Commission's description of their program at <http://www.bphc.org/whatwedo/homelessness/homeless-services/Pages/Housing-First-Initiative.aspx>, as well as <http://www.fobh.org/what-we-support/housing-first/>.

requirements of any tenant: do not disturb the neighbors and do not destroy the premises. Several cities that have instituted this program have realized significant reductions in overall expenditures, including for health care and even housing.²⁹ Nevertheless, once again, health insurers and provider organizations do not regularly cover, contribute to the funding of, or offer these services.^{30, 31}

²⁹The costs of homelessness include hefty health care costs, leading Denver's Housing First Program, Road to Home, to link funding through government and private entities.

Detox admissions for homeless substance abusers fall 84 percent when they are targeted for housing and services, said Jamie Van Leeuwen, a Denver Department of Human Services official who is manager of Denver's Road Home. Those homeless were each averaging 70 detox admissions a year, which means the savings are substantial.

M. Booth, *Four years into a 10-year plan to end homelessness in Denver, the mayor cites the cost savings as 1,500 units have opened up*, Denver Post (May 15, 2009, updated May 6, 2016). The cost of homelessness bears directly on health care costs and health care entities and insurers should participate monetarily as it is in their interest to reduce health care expenditures.

Living on the streets isn't cheap: Each chronically homeless person in Central Florida costs the community roughly \$31,000 a year...The price tag covers the salaries of law-enforcement officers to arrest and transport homeless individuals —largely for nonviolent offenses ... —as well as the cost of jail stays, emergency-room visits and hospitalization for medical and psychiatric issues. In contrast, providing the chronically homeless with permanent housing and case managers ... about \$10,000 per person per year, saving taxpayers millions of dollars during the next decade....The findings are part of an independent economic impact analysis....

"The numbers are stunning," said the [Florida] homeless commission's CEO, Andrae Bailey. "Our community will spend nearly half a billion dollars [on the chronically homeless], and at the end of the decade, these people will still be homeless. It doesn't make moral sense, and now we know it doesn't make financial sense."

K. Santich, *Cost of Homelessness in Central Florida? \$31K Per Person*, Orlando Sentinel (May 21, 2014). In Denver, the estimate of savings ran about \$23,000 per homeless person. M. Booth, *Ibid*.

³⁰ Supported housing also reduces use of expensive inpatient services, thereby having the long-term potential of saving insurers and taxpayers money. National Center on Family Homelessness, *The Minnesota Supportive Housing and Managed Care Pilot: Evaluation Summary* (March 2009), at 17 (inpatient behavioral health service costs were lower for pilot participants than comparison group; inpatient medical costs for adults in families also were lower). In addition, positive health outcomes were achieved, e.g. reduction in mental health symptoms of and substance use by participants and life-saving treatment of unaddressed medical needs. *Id.* at 12 and 18.

³¹ "Partnering" with community organizations that merely refer patients to underfunded public programs, like Section 8 for housing, does not come close to addressing social determinants of health. Rather, insurers need to cover the costs of social determinants of health because they are health care costs and affect their bottom line

Peer supports show promise for increasing the quality of care.^{32,33} Meditation is a low cost intervention that is underused and usually not covered by insurers.³⁴ Another healthcare approach that reduces healthcare expenditures involves use of either peer support³⁵ or home companions to encourage persons to exercise. We have an obesity epidemic in this country, which results in numerous conditions like diabetes, heart disease, and joint issues. Exercise has been identified as a key component to improving health generally and a major contributor to lowering health care costs³⁶. In fact, exercise is sometimes identified as the most promising approach to dealing with mental and medical conditions. For example, the medication used to treat dementia is extremely expensive and has very modest, if any, success. Exercise, on the other hand, has been shown to improve the cognition of persons with dementia.³⁷ Yet, at best, most physicians

³² See, e.g., P. Corrigan, *et al.*, *Using Peer Navigators to Address the Integrated Health Care Needs of Homeless African Americans with Serious Mental Illness*, 68 Psych. Serv. 264 (2017)(finding significant impact compared to control group with respect to general health status, psychological experience of physical health, recovery, and quality of life); P. Corrigan, *et al.*, *Using Peer Navigators to Address the Integrated Health Care Needs of Latinos with Serious Mental Illness*, <https://ps.psychiatryonline.org/doi/pdf/10.1176/appi.ps.201700241> (last accessed 3/8/17); E. Kelly, *et al.*, *Integrating behavioral healthcare for individuals with serious mental illness: A randomized controlled trial of a peer health navigator intervention*, 182 Schizophrenia Research 135 (2017)(finding that, as compared to the control group, patients with peer providers showed a decreased preference for emergency and urgent care, an increased preference for primary care clinics, improved detection of chronic health conditions, and reductions in pain).

³³ The National Health System of England guidelines for common mental health conditions recommends “befriending” for all mental health conditions. Befriending is defined as meeting and talking with someone with a mental health problem usually once a week....The befriender may accompany the befriender on trips to broaden their range of activities and offer practical support with ongoing difficulties.” <https://www.nice.org.uk/guidance/cg123/chapter/1-Guidance> and <https://www.nice.org.uk/guidance/cg123/chapter/Appendix-E-Glossary> (last accessed Oct. 10, 2018).

³⁴ The National Health System of England guidelines for recommends for generalized anxiety disorder the use of “applied relaxation,” which focuses on applying muscular relaxation in certain situations. It usually consists of 12 to 15 weekly sessions, each lasting an hour. <https://www.nice.org.uk/guidance/cg123/chapter/1-Guidance> (last accessed Oct. 10, 2018).

³⁵ A. Muralidharan, *et al.*, *Impact of Online Weight Management With Peer Coaching on Physical Activity Levels of Adults With Serious Mental Illness*, 69 Psych. Serv. 1062 (Oct. 2018) (finding that the use of peer coaches significantly increased total physical activity over usual care and over a Web-based weight management program).

³⁶ A key distinguishing characteristic of the health behavior of persons with lower health care costs was participation in active or competitive sports, consistent with the role of physical activity in slowing the impacts of biological aging and consequently suppressing medical expenditure growth. F. Navarro, *Medical Expenditure Effects from Increasing Behavioral Conformity to Patterns of Health-Related Behavior*, 1, 12 (Oct. 2015).

³⁷ C. Grout, *et al.*, *The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials*, 25 Ageing Research Rev. 13 (2016).

will do nothing more than recommend exercise in passing and without any support for or particulars about how to actualize the recommendation. This approach is ineffective. Motivating exercise using home companions and peer support³⁸ is much more likely to result in compliance at considerably less expense than, for example, treatment for cardiac conditions.³⁹

Telehealth does not fall into the category of innovative services, though some consider it to be so. Telehealth must be used with caution and protections for insureds. Patient consent to use telehealth, particularly for psychotherapy, should be required. Telehealth providers should not be counted for the purposes of determining network adequacy. Otherwise, we end up with health care networks that lack providers who give in-person care. To the extent telehealth is employed, providers must be acquainted with local resources and practices or their advice and referrals may be incorrect or impractical.

Social determinants of health

We can no longer expect to reduce health care costs unless social determinants of health are addressed.⁴⁰ As noted in the Massachusetts Health Policy Commission's summary of its 2016 cost trends hearing: "Properly addressing social determinants of health requires investment but has the potential to produce long-term cost savings and increase overall wellness."⁴¹ At the March 28 hearing, Commissioner Sudders suggested that we look to

³⁸ Exercise groups that foster social connections and are appropriate for the individual are key to exercise adherence. C. Farrance, *et al.*, *Adherence to Community Based Group Exercise Interventions for Older People: A mixed-methods systematic review*, 87 Preventive Med. 155 (2016).

³⁹ V. van der Wardt, *et al.*, *Adherence support strategies for exercise interventions in people with mild cognitive impairment and dementia: A systematic review*, 7 Prev. Med. Rep. 38 (2017)(reminders and support to overcome exercise barriers among the strategies to promote adherence); *see also*, H. van Alphen, *et al.*, *Barriers, motivators, and facilitators of physical activity in dementia patients: A systematic review*, 66 Arch. Geron. and Geriatrics 109 (2016).

⁴⁰ See, e.g., F. Jacka and M. Reavley, *Prevention of Mental Disorders: evidence, challenges, and opportunities*, 12 BMC Med. 75 (2014).

"... in the case of mental health, the determinants of poor mental health largely exist outside of the health sector..."

"...there is a need for governments, other policy makers and business leaders to fully recognize the impact of poverty and social disadvantage, environmental determinants of health and educational and workplace policies on the mental health of the population."

⁴¹ Massachusetts Health Policy Commission, Annual Health Care Cost Trends Hearing, 2016 CTH Executive Summary, at 6. See also, M. Bush, *Addressing the Root Cause: Rising Health Care Costs and Social Determinants of Health*, 79 N.C. Med. J. 26 (2018). The Commission's report also noted that capitated budgets, which are based on current services that do not include addressing social determinants of health, are a barrier to addressing these cost drivers. *Ibid.* at 11.

outcomes in other countries. A recent study from Canada found that spending on social determinants of health produces better outcomes than increases in spending on traditional health care.⁴²

Merely partnering with community groups that can refer patients to underfunded public agencies is not enough. This requires insurers to cover expenses not within the medical model of care.^{43,44} Insurers must contribute funds to redress social issues like the lack of housing (e.g., by paying rental deposits and rent subsidies), food instability, and environmental factors that reduce the ability to exercise or experience fresh air in nature. Given that insurers ultimately will benefit from reduced health care expenditures from the commitment of their funds to social determinants of health, it is reasonable to require them to invest in and cover the costs that will result in these reduced expenditures.⁴⁵

When considering performance improvement plans and certifying ACOs, MHLAC suggests that the HPC consider whether or not innovative services such as those listed above and others are being provided or covered.

Health Care Delivery Systems

An emphasis on the provision of services that are “evidence-based” can, ironically, do a disservice to patients and society at large charged with paying for services. Financial incentives underlying research funding tends to result in “evidence” about products that

⁴² D. Dutton, *et al.*, *Effect of provincial spending on social services and health care on health outcomes in Canada: an observational longitudinal study*, 190 Canadian Med. Assoc. J. e66 (Jan. 2018). The findings in this study and n. 33 *infra* are pertinent to the question of whether increased spending on health care has resulted in better health outcomes.

⁴³ While some responsibility lies with the government, e.g. employment protection laws, access to firearms, and progressive taxation policies, responsibility for other social determinants that result in lower mortality rates and better health outcomes in other countries could be part of insurers’ responsibility, e.g. promoting physical activity, providing social support through peer services, housing and food support. See, e.g., M. Avendano and I. Kawachi, *Why Do Americans Have Shorter Life Expectancy and Worse Health Than Do People in Other High-Income Countries?*, 35 Ann. Rev. Pub. Health 307 (2014) for social determinants of health that improve outcomes in other countries.

⁴⁴ In addition to insurer contributions, “community benefits” payments, as well as payments rendered in the Determination of Need process, which are typically used at present for capital improvements could be redirected to fund the programs and services that address social determinants of health.

⁴⁵ MHLAC supports the inclusion of social determinants of health in the HPC’s ACO certification and renewal process. However, the HPC should require more than just the establishment of a referral system, which regularly is ineffectual in addressing these health factors.

generate income for pharmaceutical companies. Meanwhile, promising and less expensive practices from which corporate interests do not stand to gain are neglected and remain inadequately supported by research. On the other hand, financial incentives and delivery system reforms are touted notwithstanding they do not meet the tests of efficacy in reducing cost AND improving care required of innovative services.⁴⁶

This hypocrisy is exhibited in the uncritical promotion of physical and mental health service integration.⁴⁷ The research on delivery systems that show improvements in care or cost savings often cannot attribute the improvements to the delivery model itself. Rather improvement may be attributable to additional or altered services that have been incorporated and which could be incorporated in other delivery systems without adopting potentially damaging payment incentives.⁴⁸

Furthermore, there is no evidence that the overall healthcare of persons with psychiatric diagnoses improves by virtue of information sharing by mental health and physical health providers. In fact, the opposite is true. Stigma associated with psychiatric diagnoses and well-documented undue attribution of physical symptoms to mental illness in persons with psychiatric histories undermines care.⁴⁹ Attached is a white paper on this issue

⁴⁶ See, e.g., fn. 1, *supra*.

⁴⁷ Studies show very variable results from the integration of mental and physical health care, both in terms of cost savings and quality. In those studies where improvements are seen, the improvements result from the addition of added resources or from other factors not related to integration per se. See, e.g., S. Hetrick, *et al.*, *Integrated (one-stop shop) youth health care: best available evidence and future directions*, https://www.researchgate.net/profile/Alan_Bailey/publication/321169071_Integrated_one-stop_shop_youth_health_care_best_available_evidence_and_future_directions/links/5a139d200f7e9b1e573092ba/Integrated-one-stop-shop-youth-health-care-best-available-evidence-and-future-directions.pdf (2017) (finding a portion of youth showed no benefit or decline in condition and study deficiencies like the lack of a control group or ability to control for services offered, which varied between setting and individual clinicians within settings) (last accessed 3/8/18).

⁴⁸ “Studies that did not find improved patient outcomes were generally in settings without additional personnel, training, and oversight or had small sample sizes.” M. Gerrity, *Evolving Models of Behavioral Health Integration: Evidence Update 2010-2015* (Milbank Memorial Fund 2016) at 18. One may assume that studies that found improved patient outcomes had additional personnel, training and oversight. The review of studies also concluded that care managers with training and who consistently follow up were the ones who had a large impact on mental health outcomes and the limited reported medical outcome results, the latter of which were tenuous. The impact of collaborative case management (CCM) on medical outcome varied across the studies reviewed. *Id.* at 14. Even with respect to mental health outcomes, “[based on high-quality evidence, CCM results in small to moderate improvements in symptoms from mood disorders and mental health-related quality of life.” *Id.* at 18.

⁴⁹ G. Thornicroft *et al.*, *Discrimination in Health Care Against People with Mental Illness*, 19 INT’L REV. PSYCHIATRY 113 (2007) (discussing discrimination in health care against people with mental illness); 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

entitled “EHR: Healthy for Whom?,” which details the impact sharing of physical and mental health information can have on the physical health care provided to persons with psychiatric diagnoses.

Administrative costs

The cost of payment systems should be included in evaluating cost drivers, as noted by Dr. Berwick at the March 8, 2017 HPC hearing. The cost of private insurance as compared to a public model is important to investigate,⁵⁰ as some estimates of the additional administrative costs of privatized health care run as high as 46%.⁵¹ Other models of health care delivery permit costs reductions without directing these budget cutting efforts at denying care or shifting costs to patients.⁵²

accessed April 13, 2016). As noted in M. De Hert, *et al.*, *Physical illness in patients with severe mental disorders*, 10 *World Psychiatry* 138, 138-39 (2011), integration of physical and mental health care will not solve the problem of inferior care. The authors state that “... in developing as well as in developed countries, stigmatization, discrimination, erroneous beliefs and negative attitudes associated with SMI will have to be eliminated to achieve parity in health care access and provision.” *Id.* Even those who suggest care coordination between mental health providers and primary care physicians recognize the danger to the physical health of persons diagnosed with mental illness and recommend evaluation of integrated care programs on their actual effectiveness in reducing excess mortality risk factors. N. Liu, *et al.*, *Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy, and research agendas*, 16 *World Psych.* 34 (Feb. 2017)(citations omitted). (“Few randomized trials have tested care coordination programmes for physical health conditions and cardiovascular risk factors in adults with SMD.”) Integrated care also should be monitored for its effect on physical health care for conditions that produce discomfort or affect quality of life. As long ago as 2008, Simon Jones, Louise Howard, and Graham Thornicroft concluded that “the concept of ‘diagnostic (and treatment) overshadowing’ in patients with mental illness seems to be an important under-investigated problem.” Simon Jones, ‘*Diagnostic overshadowing*’: worse physical health care for people with mental illness, 118 *ACTA PSYCHIATR. SCAND.* 169, 170 (2008).

⁵⁰ See, e.g., M. Robinson, *Universal Healthcare Coverage Around the Globe: Time to Bring It to the United States?*, *J. Health Care Finance* at 1-10 (Winter 2016).

⁵¹ S. Woolhandler and D. Himmelstein, *Single-Payer Reform*, *Annals of Intern. Med.* at 1 (Feb. 21, 2017).

⁵² For example:

Having a single government-operated insurance plan greatly reduces administrative costs and complexity. It concentrates purchasing power to reduce prices, enables budgetary control over health spending, and guarantees all legal residents, regardless of age, health status, income, or occupation, coverage for core medical services. Canadian Medicare charges patients no copayments or deductibles for hospital or physician services. Controlling medical spending does not, the Canadian experience demonstrates, require cost sharing that deters utilization.

J. Oberlander, *The Virtues and Vices of Single Payer Health Care*, 374 *N. Engl. J. Med.* 1401, 1402 (2016)(citations omitted).

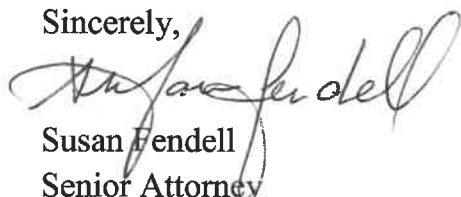
As stated by Dr. Ashish Jha at the 2018 Cost Trends Hearing, administrative costs are a key component in why the United States' health expenditures are far greater than those of other comparable countries. For this reason, it is important that *all* the drivers of health care costs be examined and on public display.⁵³ This examination is within the purview of the HPC.

Conclusion

In performing its function to lower health care spending growth, HPC should always be cognizant that utilization itself does not necessarily drive costs. Financial incentives and shifting costs to insureds to reduce expenditures by payers and insurers in the short-term often result in higher medical expenses in the long-term and reduction in the quality of care and quality of life for Massachusetts residents. Rather, HPC's performance improvement plans and ACO certification process should encourage the use of innovative services and practices by expanding the overly-narrow definition of what constitutes medical care. We recommend that the HPC scrutinize claims made about the quality and costs of delivery systems, like integrated care, and establish systems to monitor the impact of these systems on specific populations, like persons with psychiatric diagnoses,⁵⁴ before pushing the universal adoption of particular care delivery structures. Finally, the contribution of administrative costs to overall healthcare expenditures must be examined and be transparent to the public.

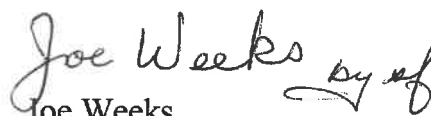
MHLAC and MaMHCA look forward to working with the HPC in helping the Commonwealth reach the goal of affordable high quality care.

Sincerely,



Susan Fendell
Senior Attorney

Mental Health Legal Advisors Committee



Joe Weeks

Director of Public Policy and Legislation

Massachusetts Mental Health Counselors Assoc.

Attachment

⁵³ An example of a valid investigation that might be undertaken was raised at the March 28 hearing by Rep. Gentile and Commissioner Altman with respect to whether pharmaceutical benefits managers drain money from health care without providing sufficient value.

⁵⁴ See *supra* at n.49 and the attached MHLAC White Paper for a description of the effect of sharing psychiatric information with physical health care providers due to implicit bias and diagnostic overshadowing.

Electronic Medical Records – Healthy for Whom?

Susan Fendell, Esq.*

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.¹ While electronic medical records have some merits, persons with psychiatric challenges have a legitimate concern about their adoption.² Persons with psychiatric

* Susan Fendell is Senior Attorney at Mental Health Legal Advisors committee (MHLAC), a state agency within the Supreme Judicial court. Ms. Fendell was a member of the Behavioral Health Task Force appointed by the Massachusetts legislature pursuant to Ch. 224. She has published in the *International Journal of Mental Health*, the *Berkeley Women's Law Journal*, and the *Journal of Health & Biomedical Law*.

¹ 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.

² 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

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.³ 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.⁴ 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.⁵ 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

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 (last visited April 7, 2015). Medical records are an 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>. In fact, more than one in four United States consumers have had their personal medical information stolen from technology systems, of whom 50% have suffered medical identity theft. F. Bazzoli, *26 percent of consumers have had health data accessed*, HEALTH DATA MANAGEMENT (Feb. 21, 2017). 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>.

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

⁴ *See id.*

⁵ *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).

[patient's] medical record.”⁶ 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 status, treatment plan, symptoms, prognosis, and progress to date.⁷

Most people presume that sharing medical records will enhance quality of care.⁸ However, for persons with psychiatric diagnoses, this is often not the case.⁹ In fact, due to stigma, providers

⁶ See 45 C.F.R. § 164.501.

⁷ See *id.*

⁸ 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).

⁹ 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 and M. De Hert, et al., *Physical illness in patients with severe mental disorders*, 10 World Psychiatry 52, 60 (2011). Life expectancy for people with major mental illness is 56 years while the “average” American life expectancy is 78 years. *Ibid.*

However, it is incorrect to presume that limited access to health care providers is the reason for reduced

often give poorer health care to persons whom they know or infer have psychiatric diagnoses.¹⁰

Stigma against persons with psychiatric histories exists in the medical profession. Physicians, psychiatrists, nurses, other mental health professionals, and medical/mental health students are

life expectancy of persons with mental illness.

Although they have two times as many health care contacts, they receive less physical check-up and screenings, less prescriptions and procedures, and less cardiovascular and cancer diagnoses, even though they have a higher risk of dying from these conditions. For example, in a study from Western Australia, although persons with SMD had the same cancer incidence as the general population, they were more likely to die from cancer.

N. Liu, *et al.*, *Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy, and research agendas*, 16 *World Psych.* 30, 31 (Feb. 2017)(citations omitted).

Patients with SMI do not receive adequate risk screening for metabolic syndrome, even screening for obesity and blood pressure. M. De Hert, *ibid.* at 55. Even oral health is affected by the attitudes of dental health teams. *Id.* at 63.

¹⁰ 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). As noted in M. De Hert, *et al.*, *Physical illness in patients with severe mental disorders*, 10 *World Psychiatry* 138, 138-39 (2011), integration of physical and mental health care will not solve the problem of inferior care. The authors state that "... in developing as well as in developed countries, stigmatization, discrimination, erroneous beliefs and negative attitudes associated with SMI will have to be eliminated to achieve parity in health care access and provision." *Id.* Even those who suggest care coordination between mental health providers and primary care physicians recognize the danger to the physical health of persons diagnosed with mental illness and recommend evaluation of integrated care programs on their actual effectiveness in reducing excess mortality risk factors. Niu, *supra* note 9 at 38, 34. ("Few randomized trials have tested care coordination programmes for physical health conditions and cardiovascular risk factors in adults with SMD.") Integrated care also should be monitored for its effect on physical health care for conditions that produce discomfort or affect quality of life, even if not potentially fatal. Unfortunately, many of the issues discussed in this paper still are not addressed by researchers and policy makers, despite the use of electronic health records and the rush to integrated care which make a person's mental health diagnosis readily available to all treating providers. For example, as long ago as 2008, Simon Jones, Louise Howard, and Graham Thornicroft concluded that "the concept of 'diagnostic (and treatment) overshadowing' in patients with mental illness seems to be an important under-investigated problem." Simon Jones, *'Diagnostic overshadowing': worse physical health care for people with mental illness*, 118 *ACTA PSYCHIATR. SCAND.* 169, 170 (2008).

among those who manifest stigmatizing bias.¹¹ Nurses, according to researchers, can act as “stigmatizers” because they believe that individuals with mental health issues are dangerous, weak and to blame information for symptoms.¹² They often do not respect or give credence to patients with psychiatric diagnoses, believing them to be poor historians, unreliable, and uncooperative.¹³ And although studies show that adherence of psychiatric patients to medication and other prescriptions is not really different from what is seen in general medical practice, both mental health and primary care providers who nevertheless believe that persons with mental illness will be non-adherent are less likely to refer their patients with mental illness to needed specialists or to renew prescriptions.¹⁴

Partially as a result of this stigma, persons with psychiatric histories on average die

¹¹ 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 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; see generally, N. Sartorius, *Iatrogenic stigma of mental illness: Begins with behavior and attitudes of medical professionals, especially psychiatrists*, 324 BMJ 1470 (2002).

¹² 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).

¹³ 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.

¹⁴ Patrick Corrigan, *et al.*, *Mental health stigma and primary health care decisions*, 218 Psych. Res. 35 (Aug. 2014).

twenty-five years earlier than the general population and sixty percent of those who die prematurely die of preventable or treatable conditions.¹⁵ 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.¹⁶ The impact of stigma on the quality of care of persons with psychiatric

¹⁵ 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). Another 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.

A more recent paper found that even controlling for lifestyle decisions, people with serious mental disease die of respiratory diseases at two to six times the rate of the general population and of infectious diseases at about two to four times the rate of the general population. In addition, they are more likely to die of diabetes and cancers. Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy, and research agendas, *supra* n.9, 16 *World Psych.* 30, 30-32 (Feb. 2017) (“studies clearly demonstrate the role of factors beyond disorder-specific and lifestyle behaviours in excess mortality”). While the authors attribute this to many intersecting causes, including failure to address medication side effects and poverty, they note that:

...poorer health outcomes could be related to providers’ negative beliefs and attitudes towards persons with SMD, including beliefs about the causes of illnesses, ability of persons with SMD to maintain an active and health lifestyle, or other beliefs about function. Mental health and primary care providers’ attitudes towards patient with SMD appear related to treatment intentions, including their likelihood of referring patients to a specialist or refilling their prescription.

Id. at 32 (citations omitted).

¹⁶ 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* n.15 (persons with bipolar disorder have double the risk of death from circulatory illnesses than the general population). These persons face problems such as patient fearfulness, system fragmentation, and significantly, provider stigma, in accessing health care for treatable conditions. Mauer

histories is not limited to cardiac conditions.¹⁷ Clinician bias against persons with mental illness often adversely affects medical management and leads to poor quality care.¹⁸ In order to learn more

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-doctors-discriminate.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.)

¹⁷ See, e.g., Mauer, *supra* note 16, 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.*

¹⁸ 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* n. 15, 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

about this disparity, Massachusetts' Behavioral Health Task Force held public forums on the topic.¹⁹ Numerous persons with psychiatric challenges recounted their inability to get appropriate physical health care because their providers were aware of their psychiatric histories.²⁰

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.²¹ 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.²² The reaction of clinicians that physical ailments are attributable to diagnosed mental

improving physician skills or attitudes toward addressing psychosocial problems or patient's serious illness concerns." Jackson, *supra*, at 1073.

While recognizing that many factors contribute to the premature death of persons with serious mental illness, including medication side effects, lifestyle, and poverty, the international authors of a paper on excess mortality of persons with SMI noted stigma and discrimination within the health care profession.

¹⁹ See BEHAVIORAL HEALTH INTEGRATION TASK FORCE, REPORT TO THE LEGISLATURE AND THE 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.

²⁰ See BEHAVIORAL HEALTH INTEGRATION TASK FORCE, *supra* note 19, at 82, 85-86 (summarizing comments regarding privacy of mental health electronic medical records).

²¹ 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.

²² 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,

health conditions also occurs due to diagnostic overshadowing, the tendency to attribute physical symptoms or behavior to a mental health condition, resulting in the failure to diagnose or treat a comorbid physical health condition. Studies document the resulting failure to diagnose and adequately treat various conditions, including ischaemic heart disease and diabetic complications.²³

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. . . .²⁴

Several studies also demonstrate the prevalence of this failure to appropriately treat persons with mental illness.²⁵ One study of 1,953 patients reviewed inappropriate admissions to psychiatric

poke fun at them on rounds, disbelieve any physical complaint they had.” *Id.* See also, Lawrence, *supra* note 15, at 157 (noting mental health practitioners “may regard complaints of physical illness as psychosomatic”) and H. Stuart, *What we need is person-centered care*, 6 PERSPECT. MED. EDUC., 146, 147 (2017)(patients with psychiatric labels “are triaged as ‘psychiatric’ regardless of their physical needs and presenting complaint”)(footnotes omitted).

²³ See generally, Simon Jones, ‘Diagnostic overshadowing’: worse physical health care for people with mental illness, 118 ACTA PSYCHIATR. SCAND. 169 (2008); H. Stuart, *What we need is person-centred care*, 6 PERSPECT. MED. EDUC. 146 (2017) (“Psychiatric labels may also get in the way of appropriate physical care as clients are triaged as ‘psychiatric’ regardless of their physical needs and presenting complaint.”)

²⁴ 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 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.)

²⁵ 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

facilities where physical diagnoses were missed. The vast majority of patients inappropriately admitted (85%) already had mental illness documented in their medical records.²⁶ 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.²⁷

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.²⁸ Veteran's Administration 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

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 MED. J. 111-15 (2010) (finding patients in psychiatric rather than medical units less likely to undergo full diagnostic assessment).

²⁶ Roy R. Reeves et al., *Unrecognized physical illness prompting psychiatric admission*, 22 ANNALS OF CLINICAL PSYCH. 180, 184 (2010), available at 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).

²⁷ *Id.*

²⁸ 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 delirium in 46% of psychiatric consultations. *Id.*

management or a sleep study, though both were indicated.²⁹

Further, undue disclosure of psychiatric information can lead to negative public health consequences, including the avoidance of necessary care³⁰ 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.^{31,32}

²⁹ Dinesh Mittal, *Understanding Provider Decision-Making*, IIR 08-086, U.S. DEP'T OF VETERANS AFF. (2013); Patrick Corrigan, et al., *Mental health stigma and primary health care decisions*, 218 PSYCH. RES. 35 (Aug. 2014) (finding that perception of likelihood of low adherence of persons with mental health diagnoses resulted in fewer referral and prescription refills by both mental health and primary care practitioners).

³⁰ 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. AUSTL. 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).

³¹ *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_in_form.

Another concern is that erroneous and stigmatizing information can be rapidly distributed.³³ 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.³⁴

³² 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).

³³ 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).

³⁴ 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 (last visited April 7, 2015); Kahn, et al., *Let's Show Patients Their Mental Health Records*, 311 J. AMER. MED. ASSOC. 1291 (2014); see also, A. Fosa, et al., *OpenNotes and share decision making: a growing practice in clinical transparency and how it can support patient-centered care*, 25 J. Am. Med. Info. Assoc. (June 2018) (finding OpenNotes improved patient satisfaction, adherence and medical decision making). Giving people greater access to their mental health records has been endorsed on the federal level as well. Health and Human Services recently

Electronic medical records do not necessarily improve health care.³⁵ Because electronic medical records often result in the storage of inaccurate, incomplete and outdated information,³⁶ patients must be able to retain control over providers' access to their mental health information, including psychiatric diagnoses, discharge summaries, psychiatric medication lists and

published guidelines concerning patient access 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.*

³⁵ 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). 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, *Doctors Are Talking: EHRs Destroy the Patient Encounter* (May 22, 2014), available at 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 33 (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; 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.*

³⁶ 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).

psychiatrist/psychotherapist progress notes.³⁷ 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.³⁸ In addition, 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.³⁹ Though doctors may have an ethical duty to disclose

³⁷ 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).

³⁸ 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.*

³⁹ 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

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.⁴⁰ Happily, today's information technology systems can provide the levels of granularity

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.

⁴⁰ 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

required to segregate psychiatric information from the rest of one's medical record.⁴¹

Doctors often cite concerns about medication interactions in justifying unrestricted access to medical records.⁴² Prescribers therefore want access to their patients' full medication lists. Of

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, which may affect readmission rates. *Id.*

⁴¹ 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 (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).

⁴² 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).

course, the utility of these lists is questionable given their error rates.⁴³ 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.⁴⁴ Now, as electronic medical record systems are being modified to accommodate capitated payment programs and associated quality 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.⁴⁵

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

⁴³ See *supra* notes 32-37 and accompanying text (detailing the likelihood of errors contained in electronic health records).

⁴⁴ See *infra* note 44 (showing websites that can be used to check for conflicts).

⁴⁵ See, e.g., DRUGS.COM, *Drug Interactions*, 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).

required from any health care providers wishing to access a person's mental health information, with few exceptions.⁴⁶ Persons with psychiatric histories are all too familiar with the repercussions 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

⁴⁶ 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

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).

of persons with psychiatric challenges must be protected by statutory and regulatory assurances that their psychiatric information will not be shared without their consent.

April 7, 2015
rev. April 13, 2016
rev. November 5, 2016
rev. July 2018