TESTIMONY OF KURT D ACKERMAN, MD, PhD, Medical Director of Adult Mood and Anxiety Services, Western Psychiatric Institute and Clinic; Assistant Professor of Psychiatry, University of Pittsburgh

Co-chairs Mr. Houston and Dr. Francis, Members of the Subcommittee on Privacy Confidentiality, and Security, and NCVHS Staff:

I am honored to have the opportunity to speak with you today regarding the impact of sharing mental health information with other medical providers, and the effect that sequestering mental health and substance use information may have on clinical practice. In reviewing recent sessions of this subcommittee, I am impressed by your understanding of the complexity of these issues and your sensitivity to the needs of medical professionals and consumers. As you are likely aware, there is tremendous interplay between general medical and psychiatric conditions. Any mind-body distinction is artificial and generally outdated. I welcome the day when mental illness loses its stigma, and we would no more consider sequestering mental health information than we would sequester information regarding neurologic, respiratory, or other medical conditions. As we have not yet reached that time, we must consider the difficult task of creating standards for exchanging sensitive health information, while respecting the privacy wishes of individuals. In the hope of advancing this aim, I will spend the balance of my testimony responding to the seven questions posed to me.

1. What different types of mental health information are there, and where are they found?

Mental health information (MHI) is relatively difficult to define. For largely practical and regulatory reasons, we currently label as mental health information any records generated in mental health programs or by mental health providers. Given that the majority of psychiatric care is currently performed outside of traditional psychiatric settings, any definition based on setting or provider would be of limited value. A more inclusive approach might define mental health information as information gathered or observed relating to a person's emotional, perceptual, behavioral or cognitive experience, as well as associated physical symptoms.

By this definition, mental health information will be found interspersed in clinical notes of virtually all clinicians, including physicians, psychotherapists, nurses, social workers, and physical and occupational therapists. Some mental health information is likely to be included in every inpatient, outpatient, and emergency room treatment record. At times, mental health care will form the majority of a clinical encounter, such as when a PCP identifies a suicidal patient and focuses the appointment on depression assessment, treatment, and development of a safety plan. At other times, mental health information might be a relatively small component of the overall note, such as a documentation of how someone is coping with their illness, or routine screening of mood disorders during a yearly physical exam.

In addition to clinical notes, mental health information is found in other areas of medical practice such as business operations units, pharmacy and insurance company records.

For the purposes of this discussion, I would suggest excluding from the definition of mental health information any medical notes, tests, procedures, imaging or laboratory studies produced in a psychiatric facility which would normally be considered medical data had the data been generated in another facility. For example, if a patient develops chest pain while hospitalized in

a psychiatric facility, any tests, labs, and consultation notes should be made available to subsequent medical providers.

2. Are there particular treatment considerations for the use and disclosure of mental health information? For example, what information should be made available about a psychiatric patient in the event that the patient comes for treatment regarding a non-psychiatric issue?

As a psychiatric consultant to medical hospitals, I have seen many instances where access to psychiatric information greatly improved the outcome of medical care, and where lack of information lead to potential or real harm to the patient. I will include just a few examples here. 1) If a heavy drinker is admitted to the hospital and does not receive thiamine/Vitamin B prior to other nutrition, he might develop a debilitating neurologic condition called Wernicke Korsakoff's Syndrome. Unfortunately, many people under-report the extent of their drinking. Accurate records would allow us to prevent this potentially debilitating complication. 2) Patients with Factitious Disorder may feign or produce medical signs and symptoms in order to assume the sick role. Knowledge of this condition allows medical teams to focus on objective signs and symptoms and limit invasive tests and procedures, and refer them for treatment of their underlying psychological problem. 3) Patients with cognitive disorders such as dementia or delirium are often unable to clearly provide their psychiatric history. Knowledge about their premorbid psychiatric history would help us to prevent behavioral and psychiatric exacerbations, and help them return to baseline; and 4) We have had multiple patients who arrive in the emergency room after an overdose and deny any intent to harm themselves. Psychiatric information is critical to determining whether this was more likely an accidental overdose or a suicide attempt.

Given that communication between psychiatry and other branches of medicine is often beneficial to patient care, the question is how much information can and needs to be shared. From the standpoint of patient privacy and trust, it would be advisable to disclose only the amount of mental health information required to adequately care for the patient's medical needs. I would propose the following categories of information be considered.

a. Medical Information. As mentioned above, I would advocate that medical data obtained in psychiatric settings, including medical consults, tests, labs, and radiographic images be classified as non-mental health information, stripped of its identifying location, if possible, and made available along with other medical information. I would also consider classifying as medical information the assessment and treatment of psychiatric symptoms which are directly related to medical disorders (e.g., treatment of behavioral health problems associated with delirium, brain injury, Parkinson's Disease, or steroid-induced mood changes). Information in this category would have confidentiality protection similar to other medical data, but would not be subject to sequestration.

b. Critical Mental Health Information. A limited amount of mental health information may be so critical to patient care that it should be made available to all providers in order to assure patient safety. At this point, I would include medication lists, allergies, non-allergic drug reactions, and dangerous behavior within medical settings in this category. Patients may be hesitant to disclose that they are on psychotropic medications; however, they are often

unaware of potential consequences with regard to drug interactions and side effects. For example, a patient may go to an infectious disease specialist to treat methicillin-resistant Staphylococcus Aureus (MRSA) pneumonia. They are being treated for depression, but don't mention that they are taking the antidepressant fluoxetine. If they are treated with linezolid for their MRSA infection, they might develop a potentially lethal hypertensive crisis. Similarly, as patients might forget prior medication experiences, it would be important to know of any history of adverse events before starting a new medication. Disclosure of medications and allergies does suggest a potential mental health history; however, many medications are used for both psychiatric and non-psychiatric purposes, and in my opinion, the benefits to patient safety outweigh other concerns. Finally, there are a small group of patients who engage in dangerous behavior in medical hospitals such as overdosing on home medications, biting, or ingesting objects. Documentation of these safety concerns should be available to all providers as the safety of the patient and others can be prevented through straightforward steps.

c. Mental Health Information for Medical Practitioners. Information necessary to support clinical decision-making of other medical professionals should be available within the general medical record, but may be sequestered at the patient's request. The details of what should be included in this "Essential Medical Data Set" need to be further developed, but might include contact information for current psychiatric providers and case managers, psychiatric diagnoses and problem lists, basic treatment plans, history of prior medication trials, drug and alcohol history, psychiatric consultations obtained in a medical setting, and perhaps an index of lethality (which would identify the most salient risk factors and protective factors for harm to themselves or others).

d. Mental Health Information Shared within a Medical-Psychiatric Team. Independent of how mental health information is made available to general medical practitioners, I would recommend maintaining open communication within systems which integrate psychiatrists and other medical professionals. For example, at the University of Pittsburgh Medical Center (UPMC), psychiatrists are an integral part of the transplant program, helping to assess the patient's suitability for transplantation, prepare them for the difficulties of transplant, and treat psychiatric issues such as delirium which are common after transplantation. Although the transplant team does not need access to all mental health information, access to the psychiatrist's recommendations can be critical. These notes would not need to be available outside of the transplant center for patients who have sequestered their mental health information. At UPMC, we also have psychiatrists embedded in HIV clinics, pain clinics, and the University of Pittsburgh Cancer Center, as well as psychiatrists providing consultation to many of the medical hospitals. In each case, the psychiatrist works closely with the medical team to assist in the care of the patient. Restricting the exchange of information between the medical and psychiatric team members would significantly limit their ability to provide adequate care. Patients should be informed that information will be shared among team members and that they could opt not to participate in the consultation process.

e. Complete Mental Health Data Set. Full access to mental health information would only be needed for a small subset of providers. Whether or not the patient has chosen to sequester

mental health information, all psychiatric information should be made available to staff responding to emergency situations (including "code responders" on a psychiatric hospital unit, and emergency department staff evaluating issues of drug toxicity and potential for the patient to harm themselves or others). Other practitioners may also need access to more complete psychiatric records. For example, a PCP taking over medication management for bipolar disorder might benefit from access to notes from the patient's prior psychiatrist. In practice, virtually any medical or psychiatric provider assuming primary responsibility for psychiatric care would benefit from reviewing prior psychiatric records; however, consumers might not wish to allow access to those records if they were changing providers due to a negative experience. Therefore, a system which requires specific consent for complete non-emergent access might be preferable.

f. Mental Health Information Excluded from Distribution. Finally, I think that some types of psychiatric information should not be distributed to other providers (even for those who do not request sequestration). I would include in this group, psychotherapy notes, and personal details of a patient's traumatic experience or other sensitive topics that are best discussed personally with the patient. Perhaps these types of informaion should not be recorded in any electronic health record, except those systems dedicated to such purposes.

3. What are the sequestration and access requirements related the use and disclosure of mental health information for non-treatment related purposes?

Several groups have access to mental health information and do not provide direct clinical treatment. These include insurance companies, business operations specialists, employers, and people involved with legal proceedings. Changes in access to mental health information would impact their functions significantly.

I cannot speak directly to the impact of sequestration on insurance companies; however, those involved with managing care would likely argue that under some circumstances, they would need access to the patient's complete medical record independent of the patient's wishes regarding sequestration. For example, individuals conducting a review of a patient's need for ongoing psychiatric hospitalization would need to understand details of the patient's condition, prognosis, treatment, and plans for discharge. Similarly, business offices of medical facilities would need to access to mental health records in order to ensure appropriate coding and billing. Employers currently have access to limited mental health information in the areas of human resources, employee assistance programs and employee health. It may be reasonable to consider additional sequestration of mental health information from employee-related health programs independent of whether a consumer supports general sharing of information. Another area of concern involves access to mental health information for medical providers involved in legal proceedings such as guardianship hearings, custody battles, and workman's compensation or disability cases. Open access to mental health information might not be in the patient's best interests, compared to the current system which requires specific consent.

4. What would implementing such controls mean for patient care as a whole?

Implementing a system which fosters communication of relevant mental health information between medical providers, while maximizing patient autonomy, would, in my opinion, greatly

improve patient care. I previously mentioned several cases in which the availability of psychiatric information had a positive impact on the care of patients who were unable to provide accurate mental health information (such as patients with delirium). If mental health information was available on a larger scale, I would anticipate improvements in both the quality of patient care and patient safety. The current system where medical and psychiatric providers maintain largely separate records is vulnerable to two types of safety issues: providers may duplicate treatment leading to unanticipated toxicity, and patients who are abusing medications can more easily obtain multiple, potentially lethal combinations of medications. It is not unusual to encounter patients who have been prescribed three medications from a similar pharmacological class, often from three separate providers. For example, a patient might receive duloxetine for chronic pain, citalopram for depression, and trazodone for insomnia. This medication combination could interact in a dangerous way, creating Serotonin Syndrome. With regard to potential abuse, patients may obtain multiple prescriptions for narcotics, sedatives, and other medications which could be sold, or if used in combination could lead to respiratory suppression and death. An open record would clearly help to minimize these problems.

Beyond the advantages of maintaining an accurate medication record, medical practitioners can make safer and more effective choices of psychotropic medications if they are aware of prior medication trials by other medical and mental health professionals. For example, a patient with a diagnosis of Bipolar Disorder may have previously developed mania when given the antidepressant sertraline. Knowledge of the patient's diagnosis and medication reaction could help prevent a similar reaction when the patient later presents to their primary care physician with depression. Coordination of care is also critical for patients with mental health symptoms related to medical disorders (such as traumatic brain injury, delirium, and dementia, or medication-induced mood disorders). For example, a patient with multiple sclerosis may require high-dose steroids to reverse an episode of paralysis. Many patients develop severe insomnia, anxiety, depression, or mania with this treatment. Within an integrated system, psychiatrists would work closely with the primary care team to manage these symptoms while allowing the patient to receive needed treatment.

Finally, a growing body of evidence suggests that the course of many medical illnesses can be influenced by psychiatric illness. For example, patients experiencing depression following a myocardial infarction (MI) have about a two-fold increase in mortality in the year following their MI than those without depression. It is easy to envision a time when cardiologists and other medical providers would alter their treatment of cardiac disease for patients exhibiting depression or consider aggressive assessment and treatment of early depression. Although most clinicians ask patients about symptoms of depression as part of routine care, making an accurate diagnosis of depression in medical patients can be difficult. For example, a patient with severe cardiac disease may report poor sleep, low energy, poor concentration, and decreased appetite. These symptoms are considered cardinal symptoms of major depression, yet might also may be seen as symptoms of their medical illness. Having access to information from psychiatric professionals may be helpful to determine their risk of depression and need for treatment.

The other side of implementing an open system with limited patient controls is the impact that it might have on patient disclosure and trust. Mental health information is among the most sensitive and personal elements in the medical record. Consumers have experienced a long history of tight controls within a predominately paper-oriented health system. A substantive change in access would require that we educate them regarding both their rights and limits of sequestration as well as the potential benefits of sharing information between medical providers.

It is also critical that consumers trust that the information they disclose is accurately recorded and protected from misuse. To the extent that people are hesitant to trust an electronic system, they might withhold information that could be vital to treatment at the individual practitioner level, as well as for other clinicians who would be subsequently accessing the data. For example, due to fears that supervisors could access their medical records, patients might not mention their work-related difficulties and associated depression until they are severely depressed and no longer able to work.

Giving patients the ability to sequester information would likely assist in establishing patient trust. However, implementing sequestration when clinical notes contain multiple types of information poses a significant challenge. For example, due to the frequency of post-stroke depression, depressive symptoms are assessed in virtually all neurologic evaluations following a stroke. It is not clear whether all notes from stroke specialists would be sequestered, if they could somehow be redacted, or if clinicians would have to split the information into multiple notes. Equally challenging would be the task of separating different areas of sequestration. For example, under recent proposals, access to mental health information might be separately sequestered from drug and alcohol information. Assessment and treatment of substance use disorders is a critical part of psychiatry given the high rates of co-morbidity in patients with severe mental illness. Most psychiatric notes would contain at minimum a reference to current substance use. One could consider combining those two areas; however, many consumers might sequester drug and alcohol, but not mental health information. Keeping those areas linked might greatly limit the utility of sharing mental health information.

5. What limits, if any, would you recommend on the patient's control?

As mentioned above and in prior sessions, medical professionals engaging in emergent treatment or evaluation of potential suicide attempts should have the ability to override a patient's wishes and "break the glass" to view mental health information. Potential mechanisms for identifying hidden information are an issue for ongoing discussion. Similarly, limiting the granularity/fine-tuning of patient choices seems to be essential to creating a functional system. It would be extremely challenging to create a system in which patients are able to sequester individual pieces of information within notes, individual notes, or even records from individual providers or groups.

Several additional areas of restriction may need to be considered. The first is patient access to their mental health information. As a rule, mental health consumers who participate actively in treatment and collaborate on their treatment goals have a better outcome. In addition, due to concerns regarding accuracy, many consumers may want to view their records. In mental health care, patients may be depressed, psychotic or violent and could, due to their condition, easily misinterpret information in their mental health record. For example, a depressed patient might view comments from their provider as proof that they don't care about them as a person, and therefore terminate their relationship. In our psychiatric practice, when a consumer reviews their chart, we frequently have a clinician present to answer questions. Widening access to mental health information to include other medical providers would pose practical difficulties when a medical provider releases information obtained from other sources.

Another potential consideration is the appropriateness of allowing open access of mental health information to providers of patients who are involuntarily committed to a psychiatric hospital and receiving medication over their objection. Under those circumstances, it might be argued that overriding the patient's request to sequester information, which will presumably

improve our ability to identify effective treatment, would be less restrictive than potentially prolonging their hospitalization.

Finally, we need to consider the rights of family and other surrogate decision-makers to alter the patient's choices regarding sequestration if a patient loses the capacity to make medical decisions. In Pennsylvania, we currently allow surrogate decision-makers and individuals identified as health care proxies or durable power of attorneys to make emergent medical decisions when a patient loses capacity. It is unclear whether they would have the right to alter the patient's choice regarding sequestration based on new information provided by the medical team.

6. What entities are now implementing these kinds of controls, and what kinds of policies or procedures have they adopted?

I do not participate in any system in which mental health information is shared by default and patients are given the opportunity to sequester information. The closest example that I currently encounter is the electronic health record for our local medical system. Within the firewall of our computer system, labs, tests, and notes are available to all providers, including notes from psychiatric consultations performed in an acute medical setting and medical notes which contain mental health information. This information is not available outside of the medical center, and psychiatric consultation notes are generally removed prior to release of information to other facilities. Patients can elect to not answer psychiatric questions or participate in consultations, and psychiatric consultants are restricted from reporting psychiatric information obtained from other mental health records.

Outside of our medical hospitals, mental health information is protected at the level of the treatment facility. Psychiatric records from mental health facilities require a patient's written consent to release information. Even with a written release, current regulations applicable in Pennsylvania place strict limits on the type of information which can be released from drug and alcohol facilities (essentially limited to whether or not the consumer is in treatment, the nature of the treatment program, the consumer's prognosis, recent progress, and whether they have relapsed). Information cannot be divulged regarding the type and amount of substances which the person has used, any history of withdrawal, or medical complications.

7. Would a policy permitting sequestration of mental health information have other important considerations?

I believe that a policy of allowing relatively open communication among clinicians, while permitting consumers to sequester categories of information, would have a substantial positive effect on overall health care. By defaulting to relatively open access, mental health information will help other medical professionals have a broader picture of their patient's health, focus mental health treatment on established diagnoses, reduce the necessity of repeating drug trials, and increase patient safety by avoiding toxic drug combinations and established adverse reactions. The ability to sequester information may lessen some of the benefits of an open record, but would provide some degree of control to consumers who would be otherwise hesitant to provide information.

Other implications of this policy would include malpractice issues, the need for development of a viable system for sequestration, need for patient and provider education, and potential cost savings. Malpractice litigation may be affected by both sequestration and non-sequestration of data. For those clinicians caring for patients who have sequestered data, questions might arise as

to whether they should or should not have broken the glass or obtained critical information from the patient and other sources. For clinicians whose patients have allowed open access, there will be questions as to how much of a "birth to death" record a clinician would be expected to, or needs to, review.

From a technology standpoint, sequestering information with reasonable sensitivity and specificity, while not interfering with normal medical care, would be a significant challenge. As mentioned initially, I expect the amount of mental health information that can potentially be exchanged will be substantial. As technology regarding access is developed, I would hope that significant effort is put towards helping clinicians to identify the most critical areas to review.

Once a system of sequestration is developed, it will be important to educate providers on how to discuss access with their patients, and develop guidelines as to how often a patient's choice is reviewed and in what context. I anticipate that many patients' "gut reaction" would be to sequester mental health information; however, if they understood more fully the value of an integrated health system, many consumers would choose this option.

Finally, increasing communication between providers could lead to substantial cost savings. Under the current system, many tests and procedures are repeated due to lack of access to information. Some of these tests, such as brain MRIs, carry significant cost, while other tests, such as CT scans, can pose safety risks such as radiation exposure. In the end, perhaps the greatest cost savings would come from the improvements in patient care. Patients with mental illness are frequently under-treated and ineffectively treated, leading to lost productivity, and increased need for medical health care. Greater communication among providers is likely to improve outcomes and decrease the overall financial and emotional burden of mental illness.