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Improving Mental Health Treatment In West Virginia: The Case for a Mental Health Advance Directive in State Code

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Consider the following case: Mr. A, a 70 year-old man with bipolar disorder, was in the midst of an acute manic episode in which he was in a fantasy world and thought he was starring in a movie. His daughter called the police and asked them to take him to the hospital for treatment. The police checked him but let him go. They told his daughter that although he acted strangely they could not transport him to the hospital against his will, because his behavior did not present a danger to himself or others.

The next day the police found Mr. A on the street in front of his home in only his underwear. Concerned for his safety, the police decided he was a danger to himself and transported him to a hospital against his will. Seventy-two hours after admission to the hospital, physicians discharged him against medical advice because he demanded discharge. Even though he was still manic, he did not meet involuntary placement criteria. A few days later the police arrested Mr. A for driving 120 miles per hour on the interstate. His psychosis led him to believe he was in a televised NASCAR race.

Before he developed bipolar disorder, Mr. A was a quiet, gentle person. When he takes his medication, he is still that way. However, manic episodes have given him a criminal record and cost him his marriage, his career, his savings and two years of commitment in a state psychiatric hospital. Mr. A wants to prevent further damage to his life by completing

a mental health advance directive which would include a Ulysses statement (box).*

The advance directives in the West Virginia Health Care Decisions Act, the medical power of attorney and the living will, focus on end-of-life decision-making, not treatment of mental health disorders. Recognizing the need for advance directives that provide a means for patients with mental health disorders to retain control over the treatment they

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"Improving Patient Care in West Virginia by Promoting Respect and Compassion"

receive, even when they have lost decision-making capacity, over half the states have now added mental health advance directives to their state codes (West Virginia has not). These mental health advance directives allow patients to direct their mental health care treatment even when they have lost the capacity to make decisions for themselves. A component of mental health advance directives found in many, but not all, mental health advance directives is a Ulysses statement. This allows a patient with a mental health disorder who has lost decision-making capacity to obtain the treatment that he or she prefers during an episode of mental illness and to specify the treatment that he or she wants and does not want.

The advantages of a mental health advance directive for patients with a mental health disorder like Mr. A are as follows: a person with mental health disorder who has lost decision-making capacity can promptly receive treatment according to the directives in his/her mental health advance directive even though he or she does not meet involuntary commitment criteria; a patient in the middle of an acute mental illness episode with a mental health advance directive with a Ulysses statement can receive treatment even if the patient is conscience, unruly, and refusing treatment; and mental health advance directives can guide treatment for patients whose acute episodes of mental

illness land them in an emergency department or in jails. In short, a mental health advance directive with a Ulysses statement provides a mechanism for a patient with mental health disorder who lacks decision-making capacity to be treated even though he/she refuses treatment and does not meet involuntary commitment treatment criteria.

Ulysses statements are beneficial for four reasons.

- They allow early intervention and do not require that clinicians wait until the patient meets criteria for involuntary commitment.
- They avoid the likely trauma of involuntary hospitalization in a state hospital. A Ulysses statement allows patients at the first sign of an acute episode to be admitted to a private hospital.
- They avoid involuntary commitment proceedings; these proceedings can be time-consuming, highly intrusive, and demeaning.
- They may enable people suffering from an acute mental health episode to avoid police apprehension which may be violent and dangerous if the person puts up a fight.

A mental health advance directive with a Ulysses statement increases the likelihood patients will receive better treatment for their mental health disorders. Mental health advance directives provide physicians clinically useful information that can expedite and improve patient care. These directives can also enable persons to specify which treatment is unwanted because it has not worked in the past. Additionally, such advance directives allow persons to specify whom they would want to take care of their children and/or pets when they are hospitalized and are unable to do so.

Desirable Features of the Proposed West Virginia Mental Health Advance Directive

The proposed West Virginia Mental Health Advance Directive allows the person completing it to specify the types of mental health care that he/she does or does not want and the person to make mental health care decisions for the person when the person cannot make them for himself/herself.

Directive with Regard to Revocation (Initial only one of the boxes below - - the second box is the Ulysses statement)

☐ My wish is that this mental health advance directive may be revoked by me at any time.

☐ My wish is that I may revoke (change my mind about) this mental health advance directive **only** at times that I have the capacity to make my own mental health decisions. I understand that I am choosing to give up the right to change my mind at any time about anything I have written in this advance directive.

The proposed West Virginia Mental Health Advance Directive enables the person completing it to give directives as follows:

- a physician or mental health therapist whom I would like to treat me
- a facility where I would like to receive treatment
- the medications I consent to (types and dosage)
- the medications to which I do not give consent (allergies or side effects)
- instructions about short-term inpatient treatment
- instructions about transport to a provider or facility
- instructions about electroconvulsive treatment (ECT) shock therapy
- persons to be notified of my mental health treatment
- persons to be allowed to visit me, and
- instructions about alternative outpatient treatments I would like.

The person completing a mental health advance directive can also state his/her wishes with regard to temporary custody of dependents when the patient lacks decision-making capacity and is hospitalized.

The proposed West Virginia Mental Health Advance Directive allows the person completing it to specify the types of mental health care that he/she does or does not want and the person to make mental health care decisions for the person when the person cannot make them for himself/herself.

Dependents include children, supportive service animals, pets, etc. In the proposed West Virginia Mental Health Advance Directive, the person completing it can specify the person to serve as his/her mental health representative and his/her successor mental health care representative for mental health care decisions when the patient lacks decision-making capacity.

The proposed West Virginia Mental Health Advance Directive was created by a task force funded by the Albert Schenk III & Kathleen H. Schenk Charitable

Trust Foundation of Wheeling, WV. The following individuals participated on the task force:

- Heather Hoelscher, Behavioral Health Advocacy Project, Legal Aid of WV
- Suzanne Messenger, State Long-term Care Ombudsman, Bureau for Senior Services
- Alvin Moss, Center for Health Ethics and Law, West Virginia University
- Marie Newcomb-Lewis, Social Work Program, Concord University
- Chip Railing, Ohio Valley Medical Center
- Patrick Ryan, Administrator, William R. Sharpe Hospital
- David Sanders, Project Coordinator, WV Recovers
- Valerie Satkoske, West Virginia Network of Ethics Committees and Wheeling Hospital
- Shawna White, Staff Attorney, Disability Rights of West Virginia
- Cami Williamson, Consultant, Adult Protective Services, WVDHHR

The 36th Annual WVNEC Symposium on May 8, 2019 will have as its focus ethical issues in the treatment of patients with mental health disorders and will discuss the implementation of the proposed West Virginia Mental Health Advance Directive. The West Virginia Network of Ethics Committees

will work with other organizations who assisted in the drafting of the proposed WV Mental Health Advance Directive to request legislation to amend the proposed WV Mental Health Advance Directive into the West Virginia Health Care Decisions Act in the 2020 legislative session. For more information, please contact the WVNEC office at 304-293-7618.

*Case adapted from Clausen, Judy A. (2015) "Making the Case for a Model Mental Health Advance Directive Statute," Yale Journal of Health Policy, Law, and Ethics: Vol. 14: Iss. 1, Article 1. Available at: <http://digitalcommons.law.yale.edu/yjhple/vol14/iss1/1>

What the Heck is a VNOAD? West Virginia's Voluntary NonOpioid Advance Directive

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In July of 2018, the West Virginia Department of Health and Human Services issued Health Advisory 148 to provide guidance regarding the newly developed Voluntary NonOpioid Advance Directive (VNOAD). The VNOAD was established in Senate Bill 273, the Opioid Reduction Act of 2017, W.Va. Code §16-54-2.

Generically, the purpose of a nonopioid directive is to provide a vehicle through which someone who wishes to avoid being offered, prescribed, or administered opioids can both make those wishes known and have them be legally recognized. The resultant forms appear to be targeted toward persons with substance use disorders (SUDs) who wish to achieve or maintain abstinence from opioid use. In principle, such directives seem a good idea to minimize the potential for those with SUDs to misuse prescription drugs or to relapse, if in recovery. However, there are some elements of the WV VNOAD that are particularly problematic from an ethical perspective, and the West Virginia Network of Ethics Committees (WVNEC) has received questions from some of our membership expressing concern about the form. In this article, I will discuss some of the concerns raised by members of the WVNEC, add my own concerns, and mention the actions I have taken to this point to get additional information from the West Virginia Department of Health & Human Resource (WVDHHR).

There are a number of ethical and legal problems (highlighted in **bold**) with the VNOAD. It is inconsistent with other West Virginia advance directives (living will, medical power or attorney) with regard to who can complete it, the steps necessary for valid completion, and terminology. While the VNOAD is called an advance directive, it appears to be more of

a cross between an instruction advance directive (living will) and a Physician Orders for Scope of Treatment (POST) form. The form does function as an advance directive in that it refuses the offering or administration of opioid medication “including in an emergency situation where I am unable to speak for myself.” The statement is a future-oriented expression of treatment preference if the patient lacks decision making capacity, but it differs from the West Virginia living will in that it does not also require that the patient be either terminally ill or permanently unconscious prior to following the directive. Additionally, unlike West Virginia advance directives, the VNOAD does not require notarization or witnesses and **may be revoked for any reason by not only the person who is the focus of the document, but also by a medical power of attorney representative or a surrogate**. Also, the form seems to imply that **persons other than the patient can complete a VNOAD** for the patient. On the form are boxes to be checked by the person completing the form and appear to allow for the “patient, **guardian**, or **health care agent** [sic—not a recognized term in West Virginia advance directive law]” **to complete the VNOAD**. Perhaps this is to allow for parents, loved ones, and legal guardians to “protect” people from the pull of their substance use disorder. This section gives some ethical pause. If an advance directive is a statement of patients’ previously expressed treatment preferences based upon their values, then how can another person complete the form for them? **Also, the DHHR health advisory that announced the VNOAD form clearly allows for persons, other than the patient (medical power of attorney representatives or surrogates), to revoke the document for any reason**. This, too, is problematic if the document is to function as an advance directive, as only a capacitated patient can create or revoke his/her advance directive.

Finally, how can the patient for whom someone else has completed a form revoke it, if they are not to be offered opioids in the first place? To this point, **I have found no evidence that requires that the patient be made aware of the existence of the VNOAD if it was completed for them by someone else.**

In some ways, the VNOAD more closely resembles a POST form. It is immediately effective and states current treatment preferences, but it also addresses future treatment concerns. Also similar to the POST, a surrogate can complete a form for a patient who lacks capacity, and in most cases, can revoke it as well. However, the POST requires a conversation between an authorized health provider (doctor, APN, or PA) and the patient or surrogate and also requires that professional's signature. The VNOAD requires a "health care practitioner" signature but not to document that a conversation was had and to authorize a medical order. The VNOAD health care practitioner signature serves to acknowledge the receipt of the document by the health care practitioner, and then, requires the provider to file the VNOAD in the patient's medical record enabling the document to "be transferred with the patient from one practitioner to another or from one health care facility to another." In fairness, the WV VNOAD health advisory does encourage persons interested in completing the form to consult with their primary care provider or SUD treatment provider, but it also makes clear that it is not "necessary to the validity of the VNOAD." Once again, the portability of the form across settings, including in the outpatient EMS setting, is similar to that of the POST. Yet, it is not a medical order; it is an advance directive.

Under the WV Opioid Protection Act of 2017, health professionals "should" check a patient's medical record or ask the patient or surrogates about the existence of VNOADs before treating them. Legal protections are provided for practitioners who honor a patient's VNOAD or who have no knowledge of the VNOAD and prescribe or administer opioids to the patient. However, a practitioner with knowledge of a VNOAD who willfully violates a VNOAD; even in an emergency situation; may face disciplinary action by the board that regulates the health provider

and may be subject to civil and criminal liability. By essentially tying the practitioner's hands with regard to offering, let alone administering, opioids and not providing a carve out for emergencies (as Pennsylvania has), patients with severe illness or injury who have a VNOAD may find themselves in situations where they are in severe pain and may not have the capacity to revoke the VNOAD. Worse yet, those who are most vulnerable, those without a support system or surrogate decision maker, may have no one else to make such decisions for them until a surrogate can be obtained, and the physician is not legally permitted to override that VNOAD and operate in the patient's best interest. Literally, the physician will not be allowed to fulfill his/her ethical responsibility to be of benefit and do no harm.

An additional concern expressed by several WVNEC members is that people for whom the form likely was not intended, for example older patients, may complete a VNOAD in fear of becoming addicted to opioids. This concern raises questions about how this form is going to be introduced to patients, if there is education that accompanies the form, and if health professionals have been educated on the form to ensure patients are not inappropriately completing the form or having it completed for them.

Another important issue with the form is that the language does not match up with language in the West Virginia Health Care Decisions Act. The term "agent" does not appear anywhere in the Health Care Decisions Act. The terms Medical Power of Attorney Representative, Health Care Surrogate, and Guardian are defined and their appointment processes and scopes of authority explained within the Act but no mention of an "agent." While this may seem fairly innocuous, by using terms that do not appear in other WV health care statutes, the Opioid Reduction Act of 2017 provides no guidance with regard to who qualifies as an agent and what his/her scope of authority might be. Further, the use of such a term appears to be reflective of the whole-cloth borrowing of the Massachusetts form without revision to reflect WV laws and values.

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Is this an ethics consult?

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The most common question I get asked as an ethics consultant is, “Is this an ethics consult?” As a practicing clinician, I know the frustration of getting dragged into a situation that does not need my intervention; I am busy enough with my own problems. I try to take a deep breath and remember what a former mentor told me, “They are in need of help, and it is your job to see if it is your help they need or someone else’s.” Ethics consultations are similar but often have a wider range of applications and potential helpful interventions.

To better explain my personal concepts on this, we have to get a few preliminaries out of the way. First, the composition and charge of your ethics committee may be different than my own. Second, your expertise and the expertise available to you differ from my own; the answer for one institution or individual may simply not be available at another. Third, we need to be clear on what we mean by consult. Like most philosophical debates, the definition is very important. I like to take a very broad view of consultation and include things like referrals, education, and “curbsides” with the formal moral deliberations that leave clear documentation. Often when we say, “This was not an ethics consult,” we mean that it did not require formal deliberation but not necessarily that it was an easy case. Fourth, a level of empathy is needed to understand the situation that the treating team is in. You, armed with a level of professional and personal distance, can see things more clearly. At the same time, just because the correct ethical solution may seem obvious, it does not mean that it will be easy.

Now that we have that out of the way, I would like to present some of the typical cases that I get called on for consultation. I am using a modified version

of the VA CASE format (<https://www.ethics.va.gov/integratedethics/ecc.asp>) in which you Clarify the issues, Assemble the Information, Synthesize the recommendation, and Explain the synthesis. I am going to forgo the Support the consultative practice portion. For the purposes of this discussion, I am not focusing on the moral or ethical reasoning, but rather the consultant response to the request.

CASE 1: Decision Making Capacity

The medical oncology team calls about an elderly patient with a history of dementia currently undergoing chemotherapy. Surgery is being offered to the patient, but they are unsure if the patient has decision making capacity (DMC), so ethics was consulted for evaluation. What would be the appropriate resolution from an ethics consultative perspective?

Clarify: Is this only about DMC, or are other issues at play? Too often, lack of DMC is only questioned when the patient’s opinion differs from the treating team’s opinion.

Assemble: The most relevant information is whether you, as the ethics consultant, are the most appropriate person for this task. A point of contention is that some ethics committees have an institutional charge to do this, but mine does not.

Synthesis/Explanation: Autonomy is one of the most important principles in bioethics. To respect autonomy, the patient needs to have the capacity to make the decision posed to them. The next issue is, how is capacity determined and who is the most appropriate to do it? The answer to this will depend on who the consultant is and the resources available. DMC is not fixed and can come and go and the level

required is dependent on the risks and benefits of the proposed intervention; less DMC is required to choose the preferred flavor of popsicle vs. weighing the risks and benefits of undertaking experimental surgery. Our particular committee and consultative structure is poorly suited for this time of continual assessments and reassessments. Since we are unable to provide this service directly or to the highest level, what do we recommend? We educate the provider as to how to assess DMC and suggest that psychiatry consultation is a possibility at our institution. This provides an opportunity for education of the provider and allows for the highest level of care possible.

Case 2: Difficult Discharge or Long Length of Stay

The hospitalist team calls with a patient that has been admitted to the hospital for several months and has been unable to be discharged due to ongoing medical and psychosocial issues. The ethics team was consulted to evaluate possible resolutions.

Clarify: What are the barriers to discharge?

Assemble: What can be done about the barriers? Are the proper resources being utilized (e.g. social work, APS, CPS, care management, charity organizations, etc.)? Are all of the proper treatments being done? Could a treatment be optimized? Can treatments be changed to help facilitate discharge? Is there a significant amount of care fatigue?

Synthesis/Explanation: It is usually best to start with the end in mind. The goal should be the best and most ethical treatment possible for the patient. From the goal, it is possible to better clarify what would be necessary to accomplish it.

Often, the most optimized care is being provided but can feel frustrating to the caregivers. The ethics consultant should offer support to the caregivers as best as possible, and often, a reassurance of doing the right thing is all it takes. From a committee and system prospective, larger scale efforts to

prevent burn out and compassion fatigue should be considered.

Case 3: Difficulty Communicating

A surgical team calls about difficulty talking to a patient about their medical issues.

Clarify: What is meant by difficulty? Is the difficulty on the part of the medical team, the patient/family/surrogate, or a combination? Is it with all topics or with some topics? Etc.

Assemble: Who are the appropriate parties that need to communicate? What needs to be communicated? When does this need to be communicated? How can it be communicated? Why is there difficulties or friction in communication?

Synthesis/Explanation: Autonomy is accepted as a fundamental principle. Informed decision making and shared decision making are extensions of the principle of autonomy. For autonomy to be respected with informed or shared decision making, there needs to be communication between the medical team and the decision maker.

What if the issue is the medical team? Often, the medical team feels that they don't have the time, ability, desire, or resources to communicate. If this is the case, the first intervention is to educate the medical providers as to their ethical duty to the patient to communicate, even if that is unpleasant. A secondary consideration is how to help support the practitioner in communicating, and who or what services are the most appropriate to aid in this.

Should the ethics committee act as a surrogate communicator for the medical team? I am of the opinion that this is only fraught with difficulties and that the ethics consultant should not be the messenger or relay of information. For example, if the patient needs to have discussion of a possible upcoming surgery, does the ethics consultant have the request knowledge and ability to do an informed consent process? Typically, the answer is no. If the consultant does have the requisite skills, then they should likely be the surgeon.

If the problem lies mostly with the patient, then perhaps DMC needs assessment (see Case 1) or referral to patient support services, chaplaincy, etc., may be helpful. The worst possible solution is if the ethics consultant/committee is used as the enforcers of the hospital and/or practitioner desires.

Case 4: Futility of Care

An intensive care team calls with a potential consult. There is a 45-year-old woman with multiorgan system failure requiring multiple aggressive interventions, including mechanical ventilation. She is currently comatose. She had left clear instructions to her Medical Power of Attorney that she would “want everything done possible to survive.” The treating teams are feeling that further treatment would be futile.

Clarify/Assemble: Futility is a term that is often used, in my opinion, inappropriately or very imprecisely which leads to poor decision making. To begin a specific discussion of futility, it needs to be clear as to the goal and the probability of reaching it. Is the goal cure, independence, extension of life, etc.? What is the probability of achieving each goal? At what cost, financially, personally, societally, etc.? Does the treating team and the decision maker or patient have the same goal and understanding of path to said goal?

Synthesis/Explanation: The first step is to ensure that the goals or destination between the two traveling companions are the same. A frank conversation needs to then occur about the probability of success and the specifics of that path, so that a mutual decision can be reached.

An example may be that a cure for the patient is not medically possible, but the goal of the family is to support organ function as long as possible. If this goal is agreed upon, it would be hard to argue that her current medical treatment is futile since she is not imminently dying. If it is truly given that there is no possibility of cure, then the treatments will eventually become futile and not be able to continue supporting the patient, no matter how aggressive they are.

Another word of caution with the common usage

of futility is that it is very important not to confuse difficult with impossible. The ethics consultant must be aware of this, because it may be the warning of caregiver fatigue.

Conclusion: I hope that after reading these cases and my attempts of explanation, you agree that an ethics consultation is any time the phone rings. My most common intervention is education and/or referral and only a portion get a more formal, moral deliberation.

VNOAD *continued from page 5*

This article may have left you with more questions than answers. Here is what we do know. Under the Opioid Reduction Act of 2017, the West Virginia Office of Drug Control Policy (ODCP) was “responsible for creating the VNOAD and publishing the form on the WVDHHR website for public use.” The current Director of the ODCP is Bob Hansen. Mr. Hansen was not the Director of the ODCP in 2017 and was not aware of the VNOAD until I contacted him regarding the form. However, he agreed to look into the questions and concerns outlined above, and we will share his responses with the WVNEC membership when we receive them. In the interim, below you will find links to the West Virginia form, the Massachusetts form, and the Pennsylvania form. Please review the materials provided, and share your thoughts either with WVNEC or directly with Mr. Hansen at ODCP.

Until the many ethical, legal, and clinical questions about VNOAD are answered and until there is education for the public and health care providers about it, your institution might choose to discourage patients from completing one.

<https://www.wvoems.org/news/2018/jul/health-advisory-148-voluntary-nonopioid-advanced-directive> (there is an embedded link to the form at the end)

https://www.mass.gov/files/documents/2017/01/xd/non-opioid-directive_0.pdf

<https://www.health.pa.gov/topics/Documents/Opioids/Pennsylvania%20Non-Opioid%20Directive.pdf>

Calendar of Events

SAVE THE DATE!

May 8, 2019 - 32nd Annual May Symposium: Ethical Issues in Mental Health

- This annual one day program will once again be held at Stonewall Resort in Roanoke, WV. Healthcare ethics tends to focus on matters of life and death, especially at the beginning and end of life, and sometimes on the treatment of those whose cognitive capacity is diminished by illness or disability, but much less on mental health per se. Medical professionals often lack education and training on how to preserve to the greatest extent possible the autonomous decision-making rights of patients with mental health disorders (MHD). The symposium will center around the ethical duty of health providers to maximize opportunities for people with MHD to direct their own healthcare including the use of mental health advance directives as tools to empower patients to maintain control over their mental health treatment decisions during mental health crises. The keynote speaker, Pulitzer Prize winner Pam Belluck of the *New York Times* (NYT), will discuss her research that resulted in an insightful December 4, 2018 article in the Health Section of the NYT, "Now Mental Health Patients Can Specify Their Care Before Hallucinations and Voices Overwhelm Them." This symposium will also present the newly developed West Virginia mental health advance directive, proposed legislation to amend it into the West Virginia Health Care Decisions Act, and a panel discussing ethics consultation for a patient with a mental health disorder and highlighting the ethical issues in such consults. Rounding out the day will be talks on 1) the vulnerability to exploitation and abuse by surrogates, 2) the stigma of patients with mental health disorders, and 3) the ever popular breakout groups for discussion of challenging cases.

Web Courses Available:

Advance Care Planning: Why, What, and How - Advance care planning refers to a process of conversation between the physician (or other advance practice provider APP) and the patient, preferably with the patient's trusted family member or friend, about the patient's wishes for future medical treatment. This program will provide 1) a sequence of steps for physicians and APPs to create an advance care plan, 2) video demonstrations of advance care planning conversations with patients in good health and those with advanced illness, and 3) information on how to bill for Medicare patients for advance care planning discussions. Cost: \$49.00 per person and includes CE credit.

WVNEC: Completing the POST Form - Advance care planning refers to a process of conversation between the physician (or non-physician professional) and the patient, preferably with the patient's trusted family member or friend, about the patient's wishes for future medical treatment. This program identifies the advantages of POST forms for seriously ill patients, present a step-by-step approach to completing a POST form, and describe how to bill for advance care planning including POST form completion. Cost: \$25.00 per person with CE credit included in the cost.

Visit our website at www.wvnec.org for the latest information on these and other future programs.



Mission Statement: The West Virginia Network of Ethics Committees assists hospitals, nursing homes, hospices, and home health care agencies to strengthen ethics committees; provides education regarding ethical and legal issues in health care to promote ethically sound decision-making; and helps patients and families to make their end-of-life wishes known.

This is a quarterly publication of the Center for Health Ethics and Law, Robert C. Byrd Health Sciences Center of WVU, for the West Virginia Network of Ethics Committees. Questions, comments, and ideas should be submitted to:

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