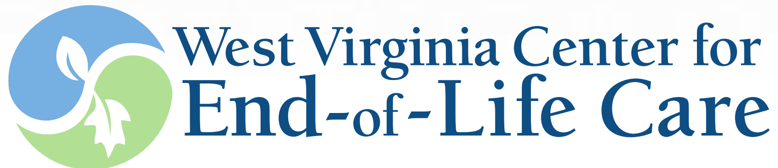
The WV Center for End-of-Life Care

Your official advance care planning organization
April 13, 2021



Danielle Funk, MS
Program Manager, WVCEOLC

Mission

The West Virginia Center for End-of-Life Care provides coordination, education, and resources so that at the end of life West Virginians will have their wishes for care known and respected.

National Health Care Decisions ~~Day~~ Month 2021

- Provide free education and resources for advance care planning
- Encourage everyone to participate in advance care planning
  - Complete a Medical Power of Attorney form at minimum
- Share the Center's services

Follow along for updates:

Wvendoflife.org

@Wvendoflife (Facebook, Instagram, Twitter, YouTube)

History

2000: The WV Legislature enacted the "Health Care Decisions Act."

2002: WV Legislature amended the Health Care Decision Act to include the POST form.

2002: On 7/1/2002, the WV Center for End-of-Life Care was officially established through support from the legislature.

2010: The WVCEOLC created the e-Directive Registry

2012: The WVCEOLC & the WV Health Information Network (WVHIN) launched the e-Directive Registry.

NEW Definition of Advance Care Planning

"Advance care planning is a *process* that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."

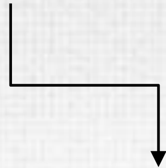
Sudore RL, et al. Defining Advance Care Planning for Adults: A Consensus Definition. *J Pain Symptom Manage*. 2017 Jan 3. [Epub ahead of print]

Purpose of Advance Care Planning

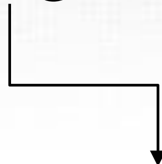
- Improve understanding of medical condition
- Identify patient's goals for care
- Name a trusted decision-maker in the event of incapacity
- Prepare for decisions that may have to be made over time

The Process

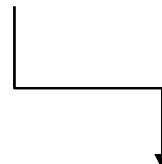
Conversation



Putting wishes on paper



Executing the advance directive



Ongoing conversation and review

Patient's Wishes Can Be Written in a Variety of Ways:

- Advance directives:
  - Medical Power of Attorney (MPOA)
  - Living Will (LW)
  - Combined MPOA/LW
  - Mental Health Advance Directive (MHAD)
- Medical orders:
  - POST form
  - Do Not Resuscitate (DNR) card
- Healthcare Surrogate

Advance Directives

- Legal documents expressing a patient's medical wishes
- Completed **in advance of** becoming sick
- Must be witnessed (2) and notarized to be valid
- Does not need a health care provider or lawyer to complete
- Cannot be honored by emergency medical services (EMS) providers
  - Ambulance/transfer between facilities
  - Emergencies

Medical Power of Attorney (MPOA)

- Legal document that allows the patient to name a person to make health care decisions on their behalf if they are unable to make them for themselves.
- Does not become effective until they are not able to clearly state their own wishes.
- Review MPOA periodically to ensure it still reflects your wishes

Living Will (LW)

- Legal document outlining how you would like to be treated if the patient became **terminally ill or permanently unconscious**.
- “Keep me comfortable without the use of life-prolonging interventions”
- In general, other states will respect a patients’ written wishes.

Combined MPOA/LW

- Just like the MPOA and LW separate forms – just together!
- Benefits:
  - One document to notarize, complete, and carry
- Disadvantages:
  - Can’t update only one part of the document

What are "Life-prolonging medical interventions?"

Living Will and Combined MPOA/LW forms:

- …if **"terminally ill or permanently unconscious"** →"Keep me comfortable **<u>without the use of life-prolonging interventions</u>**"

Non-exhaustive list:

- Cardiopulmonary resuscitation (CPR)
- The use of machines to help with heart, lung, or kidney function
- The use of feeding tubes or intravenous catheters to deliver food, fluids, blood, and medicines to the body
- Blood transfusions and antibiotics

I am giving the following SPECIAL DIRECTIVES OR LIMITATIONS ON THIS POWER: (Comments about tube feedings, breathing machines, cardiopulmonary resuscitation, dialysis, funeral arrangements, autopsy and organ donation may be placed here. My failure to provide special directives or limitations does not mean that I want or refuse certain treatments.)

____

____

NOTE: These are the patient's EXPRESSED wishes so these will always take precedence over any medical order!

Mental Health Advance Directive (MHAD)

- Psychiatric advance directive
- Recommended for patients with mental illness
- Comprehensive (7 pages) guide of patient's wishes to be honored if the patient is in a mental health crisis
  - Treatment wishes
  - Authorization for self-revocation of form while in crisis
  - Crisis response and signs
  - Substance use history
  - Temporary custody of dependents (**not the same as permanent custody determined by a court**)
  - Emergency contact
  - MPOA

What if I don't choose a MPOA representative and I lose the ability to speak for myself?

Surrogate Selection

- If you lose the ability to speak for yourself (*incapacity*) and you have not completed a MPOA, Combined form, or MHAD,
  - Your health care provider follows the Surrogate Selection Checklist.
    - Spouse
    - Adult children
    - Parents
    - Adult siblings
    - Adult grandchildren
    - Close friends
- Same rules and authority as a MPOA representative
- Chosen by a health care provider on behalf of you instead of chosen by you

Any questions on advance directives?

(More information to come shortly)

- Who is recommended to complete advance directives?
- What is the difference between a MPOA and a Surrogate Selection?
- What does “advance” refer to in “advanced care planning” or “advance directives?”

Medical Orders

- Legal documents expressing a patient's medical wishes in the form of a medical order
- Completed with a MD, DO, APRN, PA following a discussion of the patient's wishes
- Can be honored by **all** health care providers including emergency medical services (EMS) providers

- **Patients should never be provided a blank medical order to complete on their own!!!!!!!**

Do Not Resuscitate (DNR) card

- For patients who do not want CPR if their heart stops beating and/or they stop breathing

- CPR is the default. Requests for DNR status made in advance directives cannot be honored by EMS but can be honored by non-emergency health care providers.

- Can be completed at any age (18 and older) and any stage in your health condition

Date: ______

VERIFICATION OF DO NOT RESUSCITATE ORDER

Dear MD/DO/APRN/PA:

Please complete this card and with the permission of the patient, FAX the entire card to the WV e-Directive Registry, then detach at the perforation, give the bottom of the card to the patient, and keep the top in your records.

REGISTRY FAX: 844-616-1415

Last Name/First/Middle Initial: (Print legibly)

Mailing Address:

City/State/Zip:

Date of Birth (mm/dd/yyyy)

___/___/___

Last 4 SSN ☐☐☐☐ Gender ☐ M ☐ F

Date: ______

DO NOT RESUSCITATE ORDER

As treating provider of ______ (patient name) and a licensed MD/DO/APRN/PA, I order that this person **SHALL NOT BE RESUSCITATED** in the event of cardiac or respiratory arrest. This order has been discussed with ______ or his/her representative ______ or his/her surrogate decision maker ______ who has given consent as evidenced by his/her signature below.

MD/DO/APRN/PA Full Name (Printed) ______

MD/DO/APRN/PA Signature ______

Address ______

Person/Surrogate Signature ______

Address ______

Date of Birth (mm/dd/yyyy)

___/___/___

Last 4 SSN ☐☐☐☐ Gender ☐ M ☐ F

West Virginia POST

HIPAA PERMITS DISCLOSURE OF POST ORDERS TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

West Virginia POST Form

Adapted from the National POLST form and in compliance with WV Code §16-30-1 *et seq.*

Health care providers should complete this form only after a conversation with the patient or the patient's Medical Power of Attorney (MPOA) representative or surrogate. The POST decision-making process is for patients who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition, which may include advanced frailty. https://polst.org/guidance-appropriate-patients-pdf

Patient Information. **Having a POST form is always voluntary.**

THIS IS A MEDICAL ORDER, NOT AN ADVANCE DIRECTIVE. Review and revise advance directives to be consistent with POST.

Patient First Name: ____ Middle Initial: ____
Last Name: ____ Suffix (Jr, Sr, etc): ____
Preferred Name: ____ DOB (mm/dd/yyyy): ___/___/____
Last 4 Social Security Number: xxx-xx-____ Gender (circle one): M F X
Address: ____ Zip code: ____

A. Cardiopulmonary Resuscitation Orders. Follow these orders if patient has no pulse and is not breathing.

Pick 1
- ☐ YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion. (Requires choosing Full Treatments in Section B)
- ☐ NO CPR: Do Not Attempt Resuscitation. (May choose any option in Section B)

B. Initial Treatment Orders. Follow these orders if patient has a pulse and is breathing.

Reassess and discuss interventions with patient or MPOA representative/surrogate regularly to ensure treatments are meeting patient's care goals. Consider a time-limited trial of interventions based on goals.

Pick 1
- ☐ **Full Treatments (required if choose CPR in Section A).** Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.
- ☐ **Selective Treatments.** Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.
- ☐ **Comfort-focused Treatments.** Goal: Maximize comfort through symptom management; allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital **only** if comfort cannot be achieved in current setting.

C. Additional Orders or Instructions. These orders are in addition to those above (e.g., blood products, dialysis).
EMS protocols may limit emergency responder ability to act on orders in this section.

D. Medically Assisted Nutrition (Offer food by mouth if desired by patient, safe, and tolerated)

Pick 1
- ☐ Provide feeding through new or existing surgically-placed tubes
- ☐ No artificial means of nutrition desired
- ☐ Time-limited trial of ____ days but no surgically-placed tubes
- ☐ Discussed but no decision made (provide standard of care)

E. SIGNATURE: Patient or Patient Representative/Surrogate/Guardian (eSigned documents are valid)

Authorization ☐ Indicate in this box if you agree with the following statement: If I lose decision-making capacity and my condition significantly deteriorates, I give permission to my MPOA representative/surrogate to make decisions and to complete a new POST form in accordance with my expressed wishes for such a condition or if these wishes are unknown or not reasonably ascertainable, my best interests.

Opt-In ☐ Indicate in this box if you agree to have your POST and other forms submitted to the WV e-Directive Registry and released to treating health care providers to ensure your wishes are known. FAX 844-616-1415

I understand this form is voluntary. I have discussed my treatment options and goals of care with my provider. If signing as the patient's MPOA representative/surrogate, the treatments are consistent with the patient's expressed wishes or, if unknown, their best interests.

Patient/Patient MPOA representative/surrogate signature (required) | Date (mm/dd/yyyy) | The most recently completed, valid POST form supersedes all previously completed POST forms.

F. SIGNATURE: Health Care Provider (eSigned documents are valid) Verbal orders are acceptable with follow up signature.

I have discussed this order with the patient or the patient's MPOA representative/surrogate. The orders reflect the patient's known wishes, to the best of my knowledge. [Note: Only providers with MD, DO, APRN, or PA license may sign this order]

MD/DO/APRN/PA signature (required) | Date (mm/dd/yyyy): Required / / | Phone #:

Printed Full Name: required | License/Cert. #:

Send original form with patient. A copied, faxed, or electronic version of this form is a valid medical order. This form does not expire.
WV Center for End-of-Life Care: 1-877-209-8086. WV e-Directive Registry FAX: 844-616-1415 2021

Called "POLST" at the National Level

- Not for everyone; for patients who:
  - Have a serious life-limiting medical condition which may include advanced frailty
- More information and choices than advance directives and DNR card
  - CPR/DNR, level of medical intervention, artificial nutrition/hydration

Any questions on medical orders?

(More information to come shortly)

- What is the difference between a medical order and an advance directive?
- What is the difference between the DNR and the POST?

Standard of Care

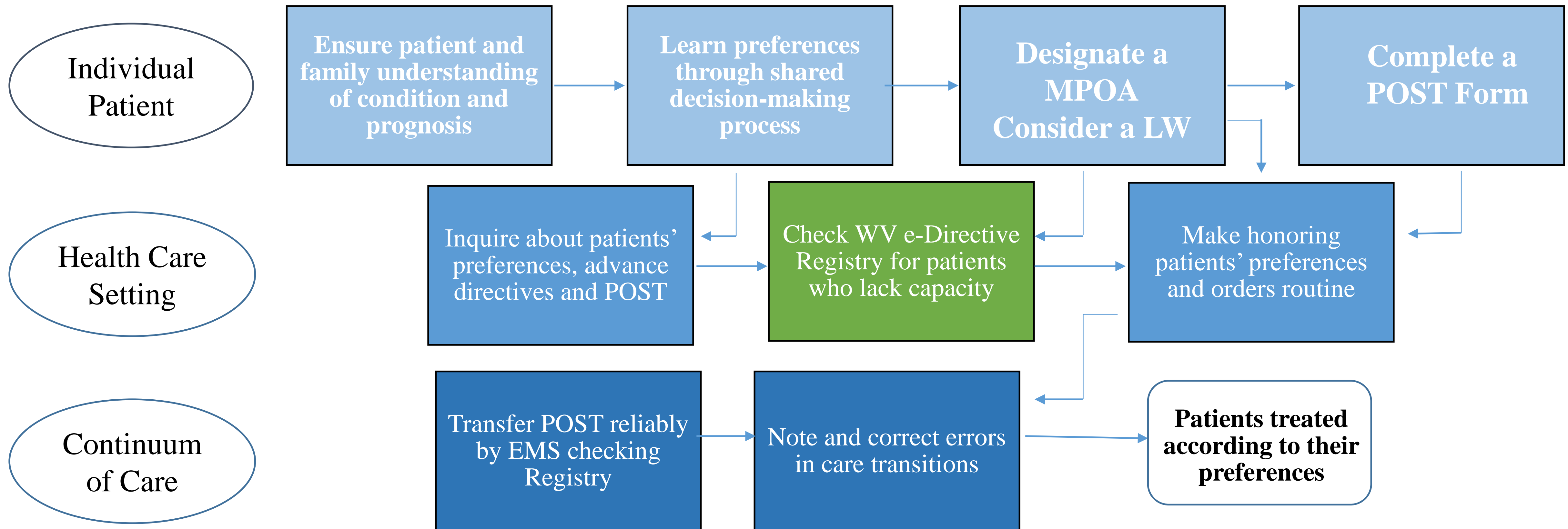
Care Consistency With Documented Care Preferences: Methodologic Considerations for Implementing the "Measuring What Matters" Quality Indicator

Kathleen T. Unroe, MD, MHA, Susan E. Hickman, PhD, and Alexia M. Torke, MD, MS, and the AAHPM Research Committee Writing Group

Indiana University Center for Aging Research (K.T.U., S.E.H., A.M.T.), Indianapolis, Indiana; Regenstrief Institute, Inc. (K.T.U., S.E.H., A.M.T.), Indianapolis, Indiana; Department of Medicine (K.T.U., A.M.T.), Indiana University School of Medicine, Indianapolis, Indiana; Indiana University School of Nursing (S.E.H.), Indianapolis, Indiana; RESPECT Signature Center (K.T.U., S.E.H., A.M.T.), Indiana University Purdue University, Indianapolis, Indiana; and Fairbanks Center for Medical Ethics (S.E.H., A.M.T.), Indiana University Health, Indianapolis, Indiana, USA

"An important marker of patient-centered care is decision quality – ensuring that medical treatments reflect the values and goals of patients who are well informed about clinically appropriate options and outcomes."
Unroe, K.T. et al., 2016

West Virginia's *System* to Provide Patient-Centered, High-Quality Care



How the WV Center for End-of-Life Care Helps West Virginians with Advance Care Planning

YOU ARE UNIQUE. YOUR ADVANCE CARE PLAN SHOULD BE TOO!

Make your wishes for medical treatment known! The West Virginia Center for End-of-Life Care is here to help you with all your advance care planning needs. The nationally-recognized Center provides coordination, education, and resources to ensure your wishes are known and respected. Whatever your wishes are, the Center is committed to serving you throughout your entire advance care plan process.

wvendoflife.org

- Learn
  - e-Directive Registry
  - The Forms
  - FAQs
- Receive
  - Free education
  - Free forms
  - Support (877-209-8086)

Meet the Forms

BACK TO WVCEOLC
ADVANCE DIRECTIVES
WV POST
WV DO NOT RESUSCITATE (DNR)
SURROGATE SELECTION
FORMS AND RESOURCES

General information:

- Advance directives are legal documents outlining patient's general wishes for medical care. These are completed in "advance" of becoming too sick to make decisions for yourself. Advance directives are recommended for everyone age 18 and older (including mature and emancipated minors).

  Requests related to cardiopulmonary resuscitation (CPR) listed in advance directives cannot be honored by emergency medical service (EMS) providers.

- Medical orders (POST and DNR) are legal documents outlining patient's wishes for specific medical care. Medical orders can be honored by all health care providers (including emergency medical service [EMS] providers).

- According to WV Health Care Decisions Act, directions provided in advance directives (i.e. the "special directives or limitations" section) take precedence over medical orders in the event that the documents are in conflict with each other.

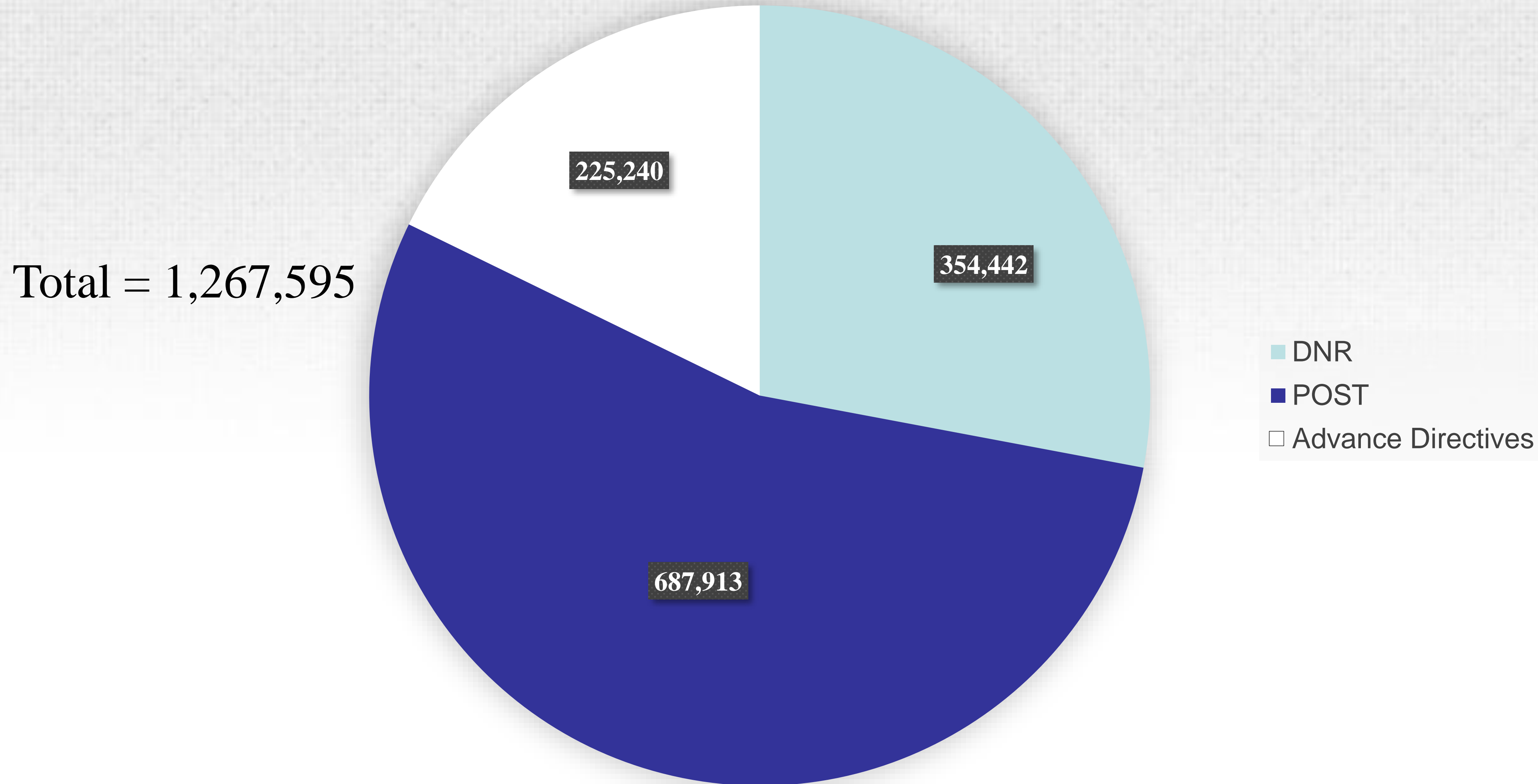
- It is strongly encouraged that all forms are submitted to the WV e-Directive Registry.

  The Registry makes patients available to treating health care providers 24/7, so patient's wishes can be honored throughout the continuum of care.

  The Registry is accessible by WV EMS providers, so they can search for medical orders regarding CPR or DNR status en route to emergencies.

  The Registry acts as the single source of truth by ensuring all documents released by the Registry are completed validly in accordance with WV health care law.

Distribution of Advance Directives and Medical Orders by the WV Center for End-of-Life Care*



*As of February 28, 2021

West Virginia Center for
End-of-Life Care

e–Directive Registry

- Accurate, relevant information available in a medical crisis
- 24/7 online access by health care providers through WVHIN
- Patients' wishes respected throughout the health care system
- Password-protected – HIPAA compliant
- **Most comprehensive registry of its kind in the nation**
- **Nationally recognized**

e-Directive Registry **FAX: 844.616.1415**

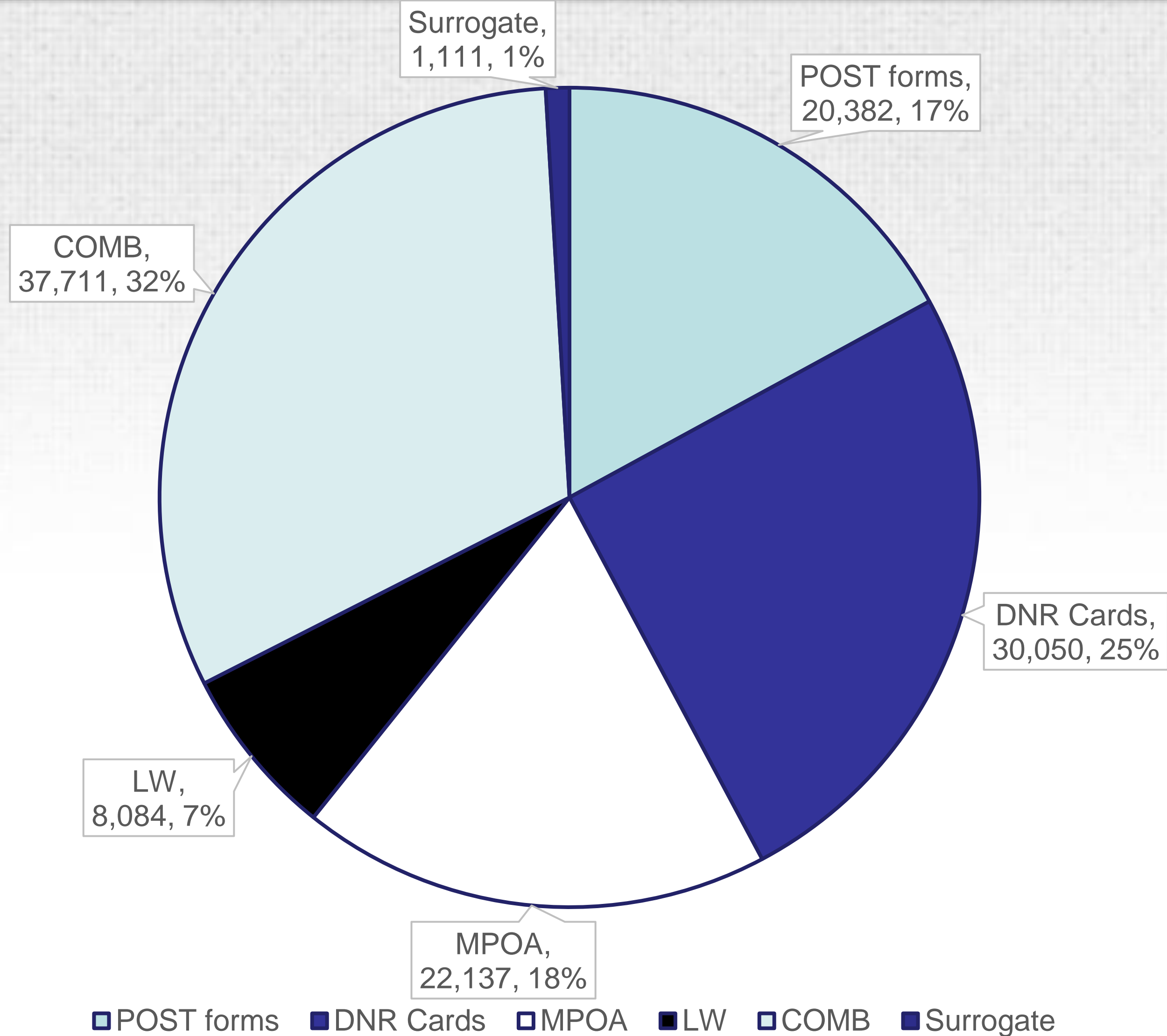
National POLST: State Registries

As of October 2020

Forms Received by the WV Center for End-of-Life Care e-Directive Registry

Total = 125,084

1. COMB
2. DNR
3. MPOA
4. POST



*As of March 31, 2021

"How COVID-19 Changed Advance Care Planning: Insights from the West Virginia Center for End-of-Life Care"

- Distributed more forms (medical orders and advance directives) in 2020 that every other year
- Communication
  - Confirmation of e-Directive Registry documents
  - Urgent desire to initiate advance care planning
  - Temporary rescindment of treatment-limiting forms
  - Patient-specific questions about honoring patients' wishes during COVID-19 social-distancing
- 16 educational opportunities

JPSM doi: https://doi.org/10.1016/j.jpainsymman.2020.09.021

Why Advance Care Planning Matters

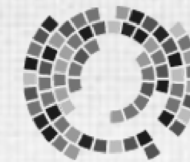
- Karen Ann Quinlain (1975)
- Nancy Beth Cruzan (1983)
- Michael Martin (1987)
- Theresa “Terri” Maria Schindler Schiavo (1990)
- Bucilla Stephenson (2012)
- Beatrice Weisman (2013)
- Bobbi Kristina Brown (2015)

What now?

- Have a conversation with your loved ones about your wishes for medical treatment.
- Complete advance directives with a NOTARY.
- Send forms into e-Directive Registry!!!
- Give to doctors, family/friends/loved ones, etc.
- Review forms regularly!
- National Health Care Decisions ~~Day~~ MONTH! (April 2021)

Thank you

The New York Times



NATIONAL QUALITY FORUM

The Office of the National Coordinator for
Health Information Technology

AARP

GAO U.S. GOVERNMENT ACCOUNTABILITY OFFICE

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Contact the Center for:

- Forms
- Education
- Resources