



West Virginia Center for
End-of-Life Care

Annual Report: 2020

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Executive Summary

Like many others experienced, 2020 was an unprecedented and unpredictable year for the WV Center for End-of-Life Care (Center). The first coronavirus, COVID-19, case in the USA was discovered in January 2020. The West Virginian Governor issued a “Stay-at-Home” order in March followed by a “Safer-at-Home” orders in May which remained in effect throughout the remainder of the year. The impact of COVID-19 changed many things during the rest of 2020 and influenced many advance care planning changes as seen through the WV Center for End-of-Life Care.

At the foundation of the Center, the goals of providing education, coordination, and resources related to advance care planning remain the focus of all efforts from the Center. The Center continued to serve the state while maintaining compliancy with social distancing for COVID-19. Danielle Funk, MS, Program Manager, provided information and resources from the Center at 16 different educational and outreach opportunities, all using remote presentation methods: seven community opportunities, six professional opportunities, and three college lectures. This is a 100% increase in educational and outreach opportunities from 2019.

The Center also distributed 48% more Physician Orders for Scope of Treatment (POST) forms, 47% more Do Not Resuscitate (DNR) orders, and 21% more advance directives than 2019. Overall, there was a 2% decrease in forms received by the WV e-Directive Registry despite an initial increase when comparing the first six months of 2020 to the first six months of 2019. These findings in addition to data from the WV e-Directive Registry were discussed in one of the two research studies published by the Center staff during 2020; this peer-reviewed journal article, *How COVID-19 Changed Advance Care Planning: Insights from the West Virginia Center for End-of-Life Care* (JPSM doi: <https://doi.org/10.1016/j.jpainsymman.2020.09.021>), utilized data from the first six months of 2020 to review trends associated with COVID-19. This research was featured in multiple media stories. The second peer-reviewed research article, *Use of a State Registry to Compare Practices of Physicians and Nurse Practitioners in Completing Physician Orders for Life-Sustaining Treatment Forms* (JPM doi: <https://doi.org/10.1089/jpm.2020.0515>), highlighted important differences in medical orders by health care provider licensure. Nurse practitioners wrote more POST orders on average and more often wrote for comfort measures.

During 2020, forms and resources were distributed across 152 cities and 8 different states including 133 cities in WV. Overall, the distribution rates were 44% higher than in 2019. The distribution data do not include the Registry mass mailing of Registry Ready information to 9,000 individuals with forms on the Registry. Despite the overall decrease in forms submitted to the Registry, there were significant increases in DNR cards, POST forms, miscellaneous forms, and e-Directive Registry sign up forms (EREG) received in 2020 compared to 2019. There was also a 50% difference in submission rates between the months of the “at home” orders in WV and holidays (April – August and December) as compared to the other months (January – March and September – November).

In the 2019 annual report, it was noted that the operating structure of the Registry, while still recognized as a national leader for registries of its kind, was in dire need of an upgrade to maintain its current level of operability with the continual increase in form submissions. Thankfully, a much needed Registry upgrade began in mid-2020 and is projected to be completed in early 2021. This upgrade will transition the Registry to a custom application format using an https interface which will address many managerial issues facing the data entry and verification process of the current Registry system. While this upgrade will not have noticeable effects to individuals other than the Center personnel, it will allow for future upgrades with more direct impact on the Registry users, both providers and patients alike.

The Center would like to offer a special thanks to WVU, Dr. Clay Marsh, and the Health Sciences Center Finance Department, specifically Paula Congelio, Dixie Paletta, Melissa Pappas, Kelley Grove, and Victoria Thomas, for their continued support and commitment to help the Center including the Registry serve its function as a unique and valuable resource to the citizens of WV and their health care providers. Also, the Center would like to express gratitude to the health care providers and patients who continue to utilize the Registry and Center and spread the information about the Center's and Registry's availability to provide help to more individuals in WV. Finally, the Center cannot understate the great appreciation for the dedication and unyielding support from Loreta Mascioli and Anne Bolyard from WVU Foundation as they continue to investigate potential avenues for additional funding to allow the Center and Registry to continue operating at the maximum level of effectiveness. Their efforts resulted in the Center receiving its first financial gift in many years when EPIC gifted the Center \$2,000 to help with COVID-19 costs. Without their belief in the Center's mission, the Center would have fewer options for future financial growth. The Center is forever thankful for all of the individuals who help support the Center's mission and improve advance care planning practices in West Virginia. To help others learn how to help support the Center, there is a new donation and support page on the Center's website: <http://wvendlife.org/support-the-center/>.

As 2020 comes to an end, the Center remains focused on improving the understanding and availability of advance care planning resources in WV and offering the very best in digitally-accessible advance care planning forms and records. Accessibility of advance care planning resources continues to be a top goal of 2021 with plans to offer free notarial services from Danielle Funk, MS. Please enjoy the 2020 Annual Report.

Best,

A handwritten signature in black ink that reads "Danielle C. Funk". The signature is written in a cursive, flowing style.

Danielle C. Funk, MS
Program Manager: WV Center for End-of-Life Care
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Introduction: WV Center for End-of-Life Care and the WV e-Directive Registry

Established in 2002 by the WV Legislature, the West Virginia Center for End-of-Life Care (the Center) provides coordination, education, and resources so that West Virginians will 1) have their preferences for care at the end of life identified and respected through advance care planning, 2) die in the setting of their choice with the option of palliative care and hospice, and 3) die comfortably with the availability of appropriate pain and symptom management. The Center distributes advance directives, medical orders, and other resources throughout the state of WV and surrounding states as requested. All of these resources are distributed free of charge to help health care providers and individuals with advance care planning.

The WV Health Care Decisions Act was enacted in 2000 and amended in 2002 to establish the Center, as previously noted, and to include the Physician Orders for Scope of Treatment (POST) form. The POST form, and subsequent POST-related educational endeavors, are monitored for quality standards by the National POLST. The Center has been endorsed by the National POLST since 2013. The WV Center for End-of-Life Care is one of only two participating POLST programs in the nation considered mature endorsed programs; the other program is California. According to the National POLST, “this is the highest level of endorsement and reserved solely for programs where use of a POLST form is a statewide part of the standard of care for appropriate persons. This is objectively measured by reviewing regional data (e.g., as defined by established criteria such as EMS, Department of Health, or the Dartmouth Atlas) and confirming that 50% or more of hospitals, nursing homes, or nursing home resident population, and hospices in each region use POLST. These programs are actively gathering data for quality assurance programs and have considered centralized POLST form databases.”

The Center, with support from the WV Health Information Network, established the WV e-Directive Registry (the Registry). With the permission of patients or their legal agents, this electronic Registry houses and makes available to treating health care providers West Virginians’ advance directive forms, do not resuscitate (DNR) cards, and Physician Orders for Scope of Treatment (POST) forms. The Registry makes patients’ treatment wishes known to their physicians so that they can be respected. The Registry serves as the “single source of truth” for patients’ advance directives and medical orders by providing accurate, relevant information available in a medical crisis to help respect the patients’ wishes throughout the health care system, 24/7 online access for health care providers through WVHIN, and maintaining HIPAA compliancy with a password-protected and dual security system.

The Registry uses an opt-in system, requiring patients’ consent to having their forms available on the Registry. This method was established at the creation of the Registry based on feedback from legal resources and the legislature. It was thought that West Virginians would be less comfortable with and less likely to accept an “opt-out” model which would result in their forms automatically being accepted on the Registry without their consent and, sometimes, awareness. Sometimes health care providers, law offices, or other professionals (including the

Office of Emergency Medical Services) automatically submit patient forms to the Registry without the patient's awareness that the Registry exists or that their forms were sent there. In this "opt-in" model, forms must either have the Registry opt in box initialed/marked, thus granting the patient's consent for the form's inclusion on the Registry, or the forms must be accompanied by a separate e-Directive Registry sign-up form either submitted newly or already on file for the patient.

The Center is highly regarded nationally among POLST programs due to the educational and outreach opportunities as well as to having the most comprehensive registry of its kind in the nation. The two registries of this kind regarded as the best in the nation are the WV e-Directive Registry and the Oregon POLST Registry. Oregon, being a larger state and having continuous funding and support from their state legislature, has the largest registry in the nation. The WV e-Directive Registry, however, is the most comprehensive registry of its kind in the nation. This accolade was achieved because the Registry accepts and houses advance directives and medical orders as well as any kind of form that the patient desires to be on the Registry whereas other registries only accept POLST forms. The Idaho registry also accepts advance directives, but it is not as large and does not provide educational outreach.

Because of the WV e-Directive Registry, the Center has been nationally recognized by the New York Times, AARP, the National Quality Forum, the Institute of Medicine of the National Academies, the US Government Accountability Office, and the Office of the National Coordinator for Health Information Technology for being a leader in registries for advance directives and medical orders.

Annual Reports

Form Names and Abbreviations in this Report:

COMB form – Combined Medical Power of Attorney and Living Will; an advance directive

DNR card – Do Not Resuscitate card; a medical order

EREG – WV e-Directive Registry sign up form

LW form – Living Will; an advance directive

MHAD – Mental Health Advance Directive; an advance directive

MISC – Any form submitted to the Registry whose form type is not already coded in the system; forms coded in the system are:

MPOA form – Medical Power of Attorney; an advance directive

POST form – Physician Orders for Scope of Treatment; a medical order

REVO – Revocation form; this is not a form with “revocation” written on it, but instead a form which is completed for the only purpose of revoking a previously completed form(s)

SS form – Surrogate Selection checklist

VNO – Voluntary Non-Opioid Advance Directive; an advance directive

Terms in Section 1 of this Report

Forms distributed – Forms sent from the WV Center for End-of-Life Care to the public and health care providers for advance care planning. Forms and resources are sent free of charge. Forms are either mailed or downloaded from the Center’s website (wvendlife.org)

DNR cards – Do Not Resuscitate orders; a type of medical order

POST forms – Physician Orders for Scope of Treatment forms; a type of medical order

Advance Directives – Includes Medical Power of Attorney (MPOA), Living Will (LW), Combined Medical Power of Attorney and Living Will (COMB), Mental Health Advance Directive (MHAD), frequently asked questions and forms packet, surrogate selection (SS), and advance care planning packets

Toll-free line – The WV Center for End-of-Life Care has a toll-free phone line (877-209-8086). Monthly reports are generated with information on the number of incoming calls and voicemails to the toll-free number. This number does not include the count of outgoing calls from the Center or incoming or outgoing calls to the Center’s other phone lines (i.e., Danielle’s direct line, calls transferred to the Center, the Center’s local number, Atticus’ number)

Website visits – The number of unique website hits to the wvendlife.org website. This number is based on the count of unique visits, but not unique IP addresses as it would exclude health care workers who frequent the website multiple times to obtain forms and help their patients with advance care planning

Section 1: WV Center for End-of-Life Care 2020 Review

Form Distribution

Since the Center was founded in 2002, the Center has distributed 345,681 DNR cards, 669,993 POST forms, and 245,425 advance directives. On average for 2002-2020, the Center distributes 18,194 DNR cards, 34,263 POST forms, and 12,917 advance directives yearly. In 2020, the Center distributed 26,667 DNR cards, 49,210 POST forms, and 18,358 advance directives. These distribution totals reflect significant increases from both the yearly averages and from 2019¹. Specifically, the Center distributed 47% more DNR cards than the yearly average and 47% more than in 2019, 44% more POST forms than the yearly average and 48% more than 2019, and 42% more advance directives than the yearly average and 21% more than in 2019. Overall, 44% more forms were distributed in 2020 than in 2019. Forms and resources were distributed in 641 separate mailings to 152 different cities and 8 different states, including to 133 West Virginia cities and 50 of the 55 West Virginia counties.

Communication

From 2002 through 2020, the Center's toll-free line² has received 35,649 phone calls. The yearly average from 2002-2019 is 1,891 calls annually. In 2020, excluding the months of November and December for which data are not yet available, 1,607 phone calls were received on the toll-free line. This is a 15% decrease from the annual average and a 10% decrease from 2019³.

Since 2002, the Center's website has been visited 734,356 times. On average, the website has been visited 38,650 times per year. In 2020, the website received 62,150 visits. Many website updates occurred in 2020 to reorganize the website, update information offered, and add more resources and information. 2020 represented a 61% increase in visits from the annual average and 1% increase in visits from 2019⁴.

In addition to the Center's standard form distribution, the Center has a separate mailing process specifically for the Registry. These mailings contain information for individuals on the Registry regarding the presence of their forms on the Registry and whether or not the forms have any errors. In 2020, the Center mailed a bulk distribution of 9,000 Registry mailings. Following the mass mailing, 45 additional Registry mailings were distributed throughout 2020. No Registry mailings occurred in 2019. The data for Registry mailings are not included in the distribution rates of 2020 for medical orders and advance directives. Due to budget constraints, the goal of an annual mass Registry mailing is not always achieved.

Education and Outreach Opportunities

The Center helps serve the state of West Virginia with advance care planning by offering educational and outreach opportunities, in addition to the other resources provided by the Center.

¹ 2019 distribution totals: 18,135 DNR cards, 33,285 POST forms, and 15,284 advance directives

² Phone call data for November and December 2020 is not yet available. Reports will be updated once the data is available.

³ 2019 phone call total: 1,775

⁴ 2019 website visits: 61,848

In 2019, eight educational and outreach opportunities were available to both health care providers and patients as appropriate. In light of the social distancing policies due to COVID-19 in 2020, the Center was able to offer 16 different educational and outreach opportunities, a 200% increase from 2019. All of these opportunities were offered virtually. Of the 16 opportunities, seven were for the general public (i.e., community), six were for health care professionals, and three were college lectures.

Research

No research studies were published in 2019 specifically utilizing the Center. During 2020, two separate studies were published based on the analysis of data from the Center.

Funk, D.C., Moss, A.H., & Speis, A. How COVID-19 changed advance care planning: Insights from the West Virginia Center for End-of-Life Care. *Journal of Pain and Symptom Management* 2020; 60(6): e5-e9. doi: <https://doi.org/10.1016/j.jpainsymman.2020.09.021>.

Constantine, L.A., Wang, K., Funk, D.C., Speis, A., & Moss, A.H. Use of a state registry to compare practices of physicians and nurse practitioners in completing physician orders for life-sustaining treatment forms. *Journal of Palliative Medicine* 2020. doi: [10.1089/jpm.2020.0515](https://doi.org/10.1089/jpm.2020.0515).

The Funk, et al. (2020) article utilized data from the first six months of 2020 compared to 2019 to review trends associated with COVID-19. This research was featured in multiple media stories and provided valuable information related to advance care planning in the unprecedented pandemic times.

The Constantine, et al. (2020) article utilized data from the Registry to highlight important differences in medical orders by health care provider licensure. Specifically, selected POST form options and form completion errors were compared by licensure, and physicians and nurse practitioners were found to differ in the frequency and type of their POST orders.

Table 1. Total form distribution by form type

Total Forms Distributed 04/01/2002 – 12/31/2020: 1,261,099	
DNR cards	345,681
POST forms	669,993
Advance Directives	245,425

Table 2. Form distribution by type in 2020

Forms Distributed 01/01/2020 – 12/31/2020: 94,235	
DNR cards	26,667 (47.05% increase)
POST forms	49,210 (47.84% increase)
Advance Directives	18,358 (20.11% increase)

Table 3. Form distribution by form type in 2020

2020 Monthly Review: 94,235												
	January	February	March	April	May	June	July	August	September	October	November	December
DNR cards	2,700	2,220	2,235	1,102	1,920	1,635	2,220	3,145	1,870	3,395	1,650	2,575
POST forms	5,210	3,265	3,860	2,877	3,091	2,855	3,670	6,570	3,545	5,622	4,210	4,435
Advance Directives	2,278	1,472	1,932	1,809	1,509	1,093	1,541	1,229	1,412	1,728	1,276	1,079

Figure 1. Total form distribution by form type

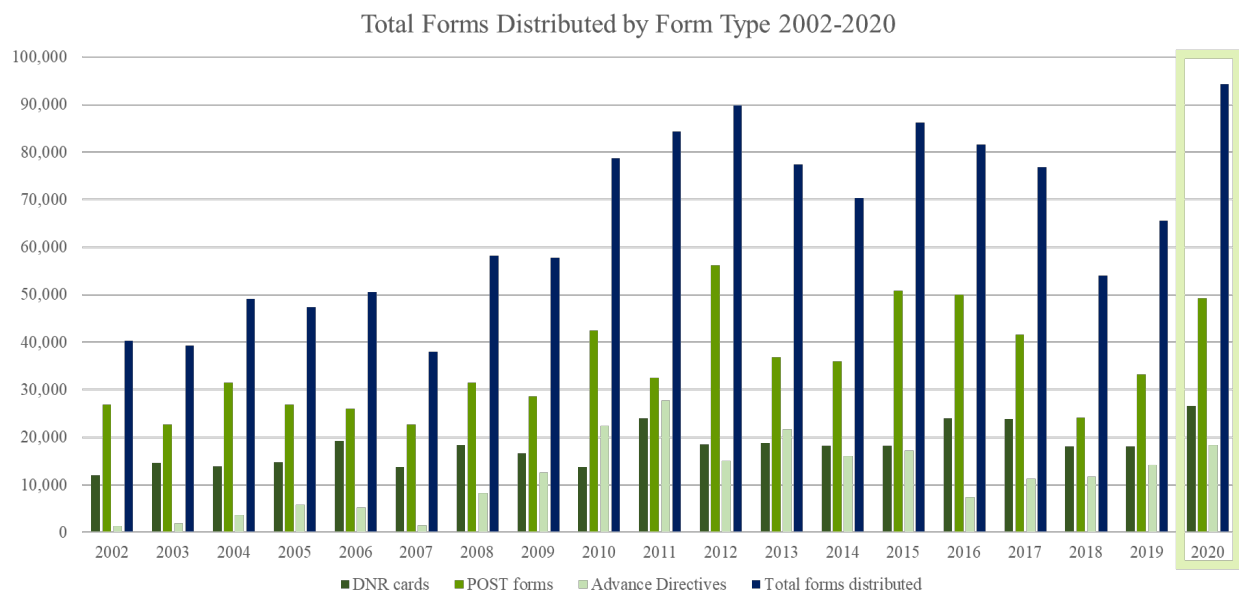


Figure 2. Total form distribution by form type in 2015-2020 (6 year trend)

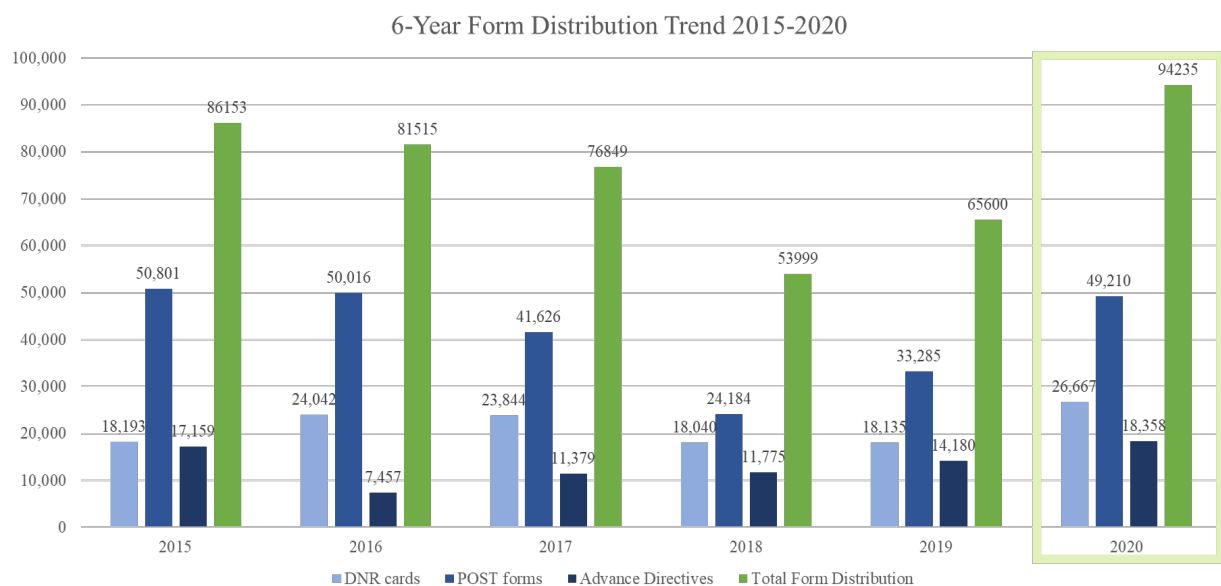


Table 4. Total communication by communication type

Total General Communication 04/01/2002 – 12/31/2020: 706,428	
Calls on the toll-free 877-209-8086 line	35,649
Website visits	734,356

Table 5. Communication by communication type in 2020

2020 Communication Review	
Calls on the toll-free 877-209-8086 line	1,607*
Website visits	62,150
Registry mailings	9,045
Non-Registry mailings	641
Educational and outreach opportunities	16

*Phone call data for November and December 2020 not yet available. Reports will be updated once the data is available.

Table 6. Education and outreach opportunities by type in 2020

2020 Education and Outreach Opportunities Review	
Community opportunities	7
Professional opportunities	6
College lectures	3

Table 7. Monthly communication by communication type in 2020

2020 Monthly Review												
	January	February	March	April	May	June	July	August	September	October	November	December
Calls on the toll-free 877-209-8086 line	170	130	300	234	109	103	134	115	81	231	0	0
Website visits	5,298	5,299	6,059	4,822	4,270	4,187	5,522	5,572	5,486	5,742	4,959	4,934

Figure 3. Total communication by communication type

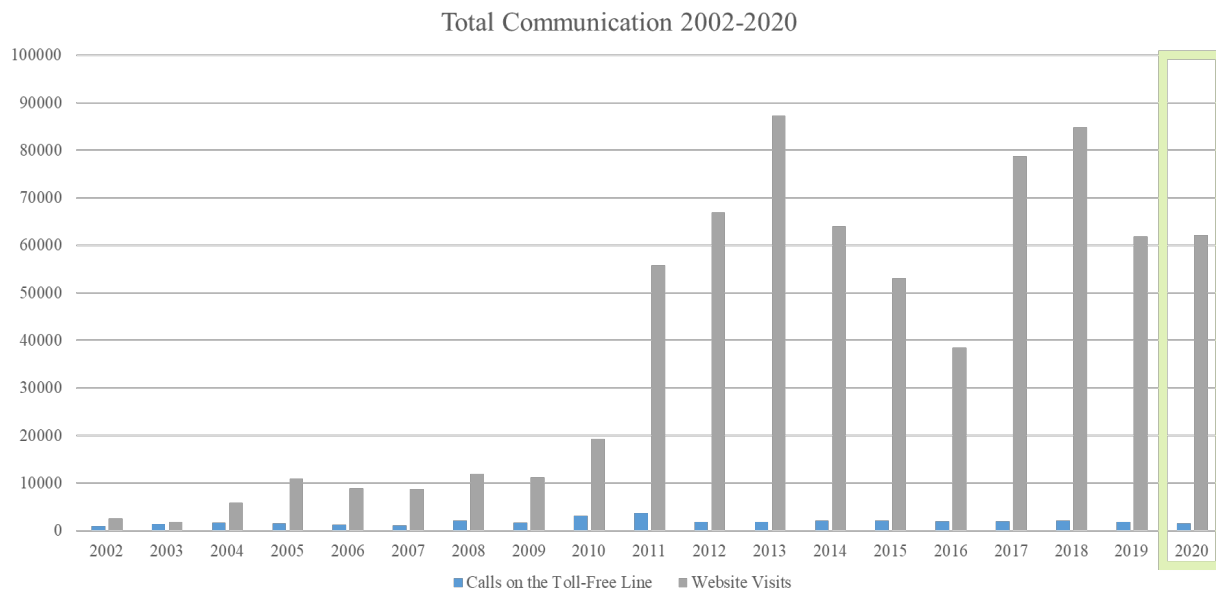
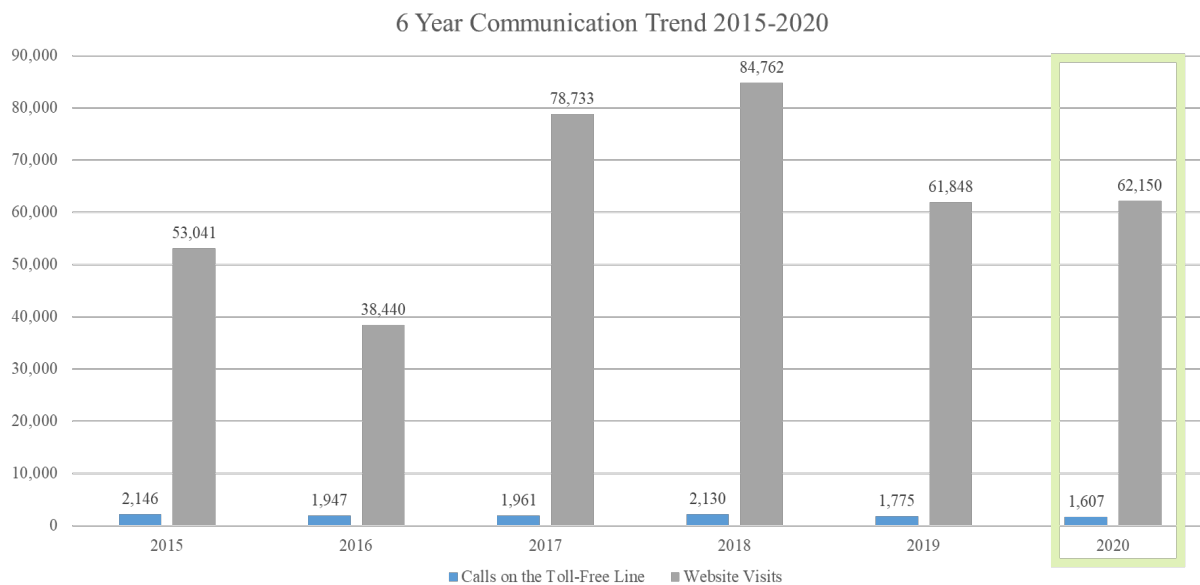


Figure 4. Total communication by communication type in 2015-2020 (6 year trend)



Terms in Section 2 of this Report

Forms received – All forms received by the WV e-Directive Registry including NRR, duplicate submissions, and archived forms

Registry forms – Forms on the WV e-Directive Registry

Registry patients – All persons with forms on the WV e-Directive Registry. The term “Patients” does not indicate that the person is currently hospitalized. “Patients” is used to distinguish between the general public (i.e. “patients”) and health care providers (i.e. “providers”)

Not Registry Ready (NRR) – Forms received by the WV e-Directive Registry that are missing required information to be appropriately recorded on the Registry or to be legally valid. Includes:

- missing demographic information, signature(s), notarization elements (advance directives only), and/or date;
- forms that are illegible, too dark/light, missing pages or parts of pages;
- forms that are not opted into the Registry and for which there are no e-Directive Registry sign-up forms on the Registry for the patient;
- forms (POST, DNR, surrogate selection) not signed by an authorized health care provider, unable to verify the provider license, unable to read provider signature/name, provider listed as a student;
- conflicting directives given in sections A and B of the POST form (“CPR” in section A with any option other than “Full Interventions” in section B);
- back of the POST form only and unidentifiable;
- more than one option selected in section A and/or B of the POST form;
- only one half (top or bottom only) of the DNR card

Registry Ready (RR) – Forms received by the WV e-Directive Registry that meet all the minimum requirements for the form type as required by law and the Registry in order to be searched on the West Virginia Health Information Network (WVHIN)

Active forms – Forms in the WV e-Directive Registry that are ready to be searched on the Registry but are not archived. Includes NRR forms

Archived forms – Forms in the WV e-Directive Registry that are no longer in effect or no longer searchable on WVHIN

All patients – All individuals (patients) on the WV e-Directive Registry with forms on the Registry

Archived patients – Patients on the WV e-Directive Registry who are not searchable on WVHIN due to death or opting out of the Registry. All forms associated with archived patients are also archived and no longer available to treating health care providers, the patients’ legal MPOA representative, or the patients’ legal health care surrogate

Section 2: WV e-Directive Registry 2020 Review

e-Directive Registry

From October 1, 2010 through December 31, 2020, the Registry received 124,181 forms of which, 67,119 are active forms, 57,062 are archived forms, 99,371 are RR forms, and 24,810 are NRR forms. In 2020 alone, the Registry received 12,813 forms consisting of 10,281 active forms, 2,532 archived forms, 10,300 RR forms, and 2,513 NRR forms. Compared to 2019, 2.27% fewer forms were received in 2020. However of the forms received in 2020, 19% more forms were active and 43% fewer were archived than 2019. There was also a 1% decrease in RR forms and a 9% decrease in NRR forms received in 2020. When comparing 2020 to 2019 by form type, 45% more DNR cards, 3% more POST forms, 200% more MHAD forms, 28% more EREG, 19% more MISC forms, and 38% more REVO forms were submitted in 2020. In contrast, 27% fewer COMB forms, 25% fewer LW forms, 12% fewer MPOA forms, and 50% fewer SS forms were submitted in 2020.

The six months with the highest forms received in 2020 were January⁵, February⁶, March⁷, September⁸, October⁹, and November¹⁰. The average of these months is 1,203 forms. The six months with the lowest forms received in 2020 were April¹¹, May¹², June¹³, July¹⁴, August¹⁵, and December¹⁶. The average of these months is 804 forms. There was a 50% change between the months with the lowest and highest number of forms received in 2020. Of importance to note, the Stay-At-Home orders in WV went into effect on March 24, 2020 followed by Safer-At-Home orders in May.

In total, there are 91,384 patients, 55,748 of which are archived, on the Registry. In 2020, 8,522 new patients were received by the Registry and 3,261 were archived. This is an 19% decrease in new patients from 2019 to 2020 and a 6% decrease in archived patients from 2019 to 2020. Currently, the youngest active patient on the Registry is younger than 18 years old, and the oldest active patient is older than 100 years old. Patients are from 3,057 different cities, with 2,203 cities being in WV. With the new patients, 693 new cities were entered into the Registry in 2020. Forms have also been submitted to the Registry from 46 different states. All 55 WV counties are represented on the Registry.

⁵ January forms received: 1,376

⁶ February forms received: 1,408

⁷ March forms received: 1,026

⁸ September forms received: 911

⁹ October forms received: 954

¹⁰ November forms received: 1,541

¹¹ April forms received: 754

¹² May forms received: 618

¹³ June forms received: 895

¹⁴ July forms received: 854

¹⁵ August forms received: 883

¹⁶ December forms received: 821

Table 8. Total forms received by classification

Cumulative Registry Form Review and Totals (10/1/2010 – 12/31/2020)	
Forms Received	124,181
Active Forms	67,119
Archived Forms	57,062
RR Forms	99,371
NRR Forms	24,810

Table 9. Forms received by classification in 2020

Cumulative Registry Form Review and Totals (10/1/2010 – 12/31/2020)	
Forms Received	124,181
Active Forms	67,119
Archived Forms	57,062
RR Forms	99,371
NRR Forms	24,810

Table 10. Cumulative patient totals by classification

Cumulative Registry Patient Review and Totals (10/1/2010 – 12/31/2020)	
All Patients	91,384
Archived Patients	55,748

Table 11. Patient totals by classification in 2020

2020 Registry Patient Review and Totals	
New Patients	8,522 (18.19% decrease)
Archived Patients	3,261 (6.29% decrease)

Figure 5. Total forms received by classification

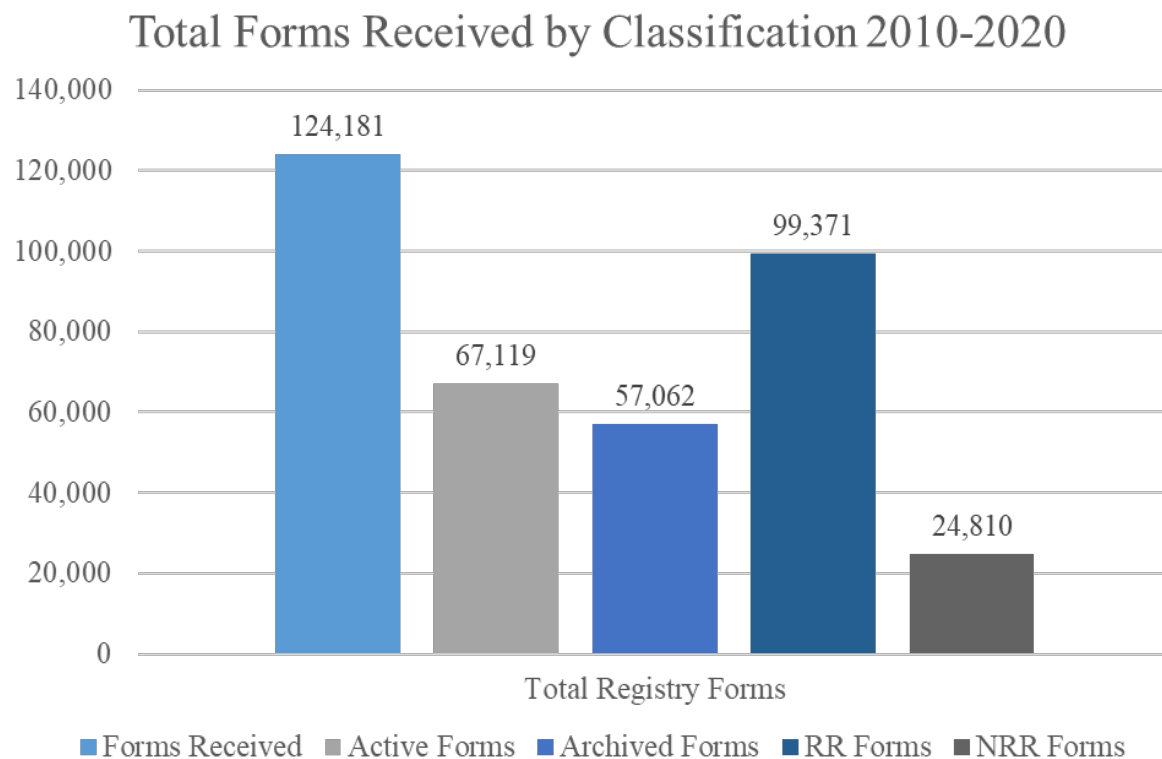


Figure 6. Forms received by classification in 2020

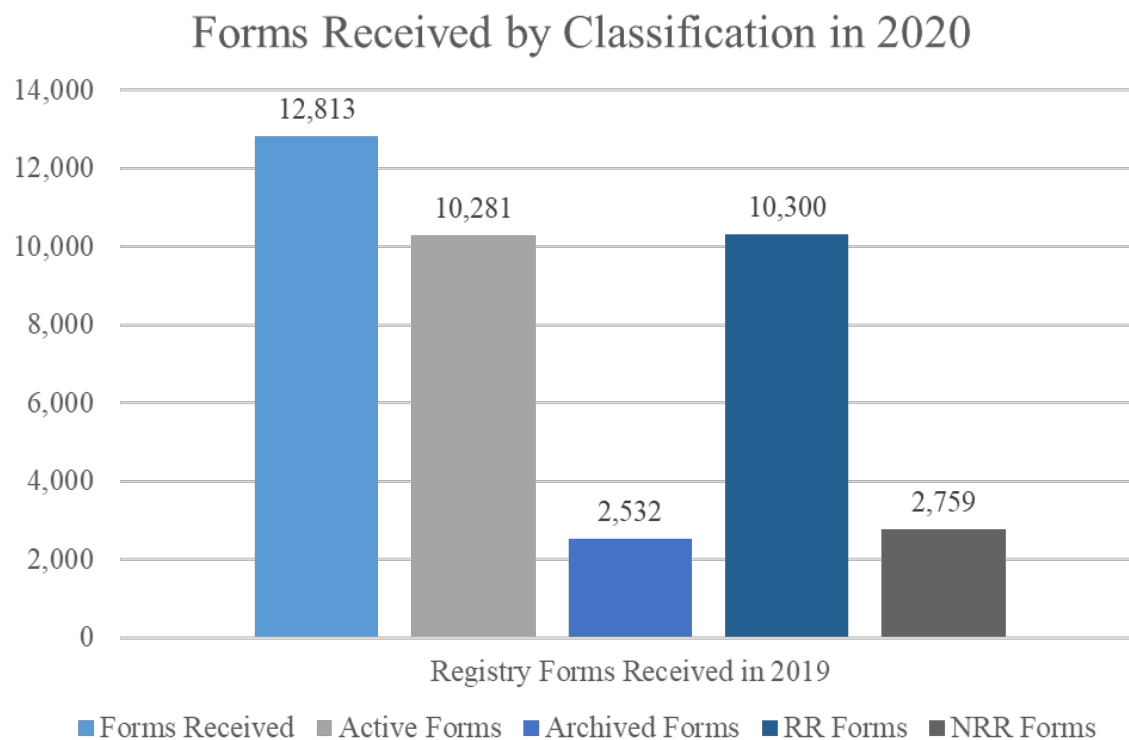


Figure 7. Total Registry patients

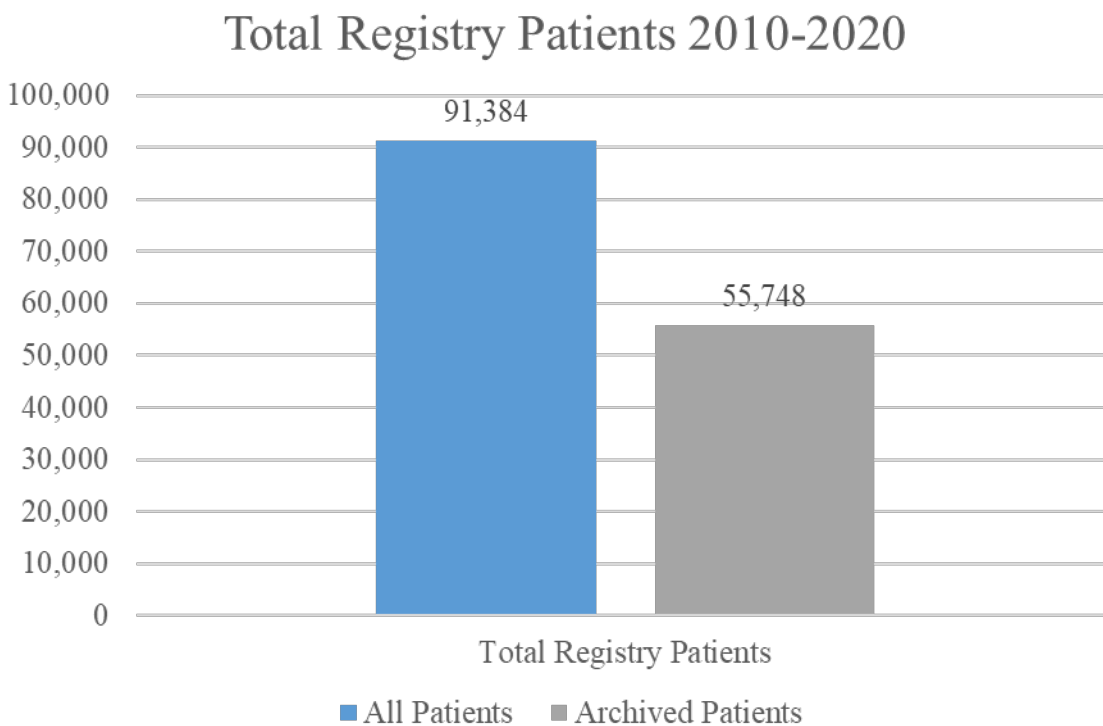


Figure 8. Registry patients in 2020

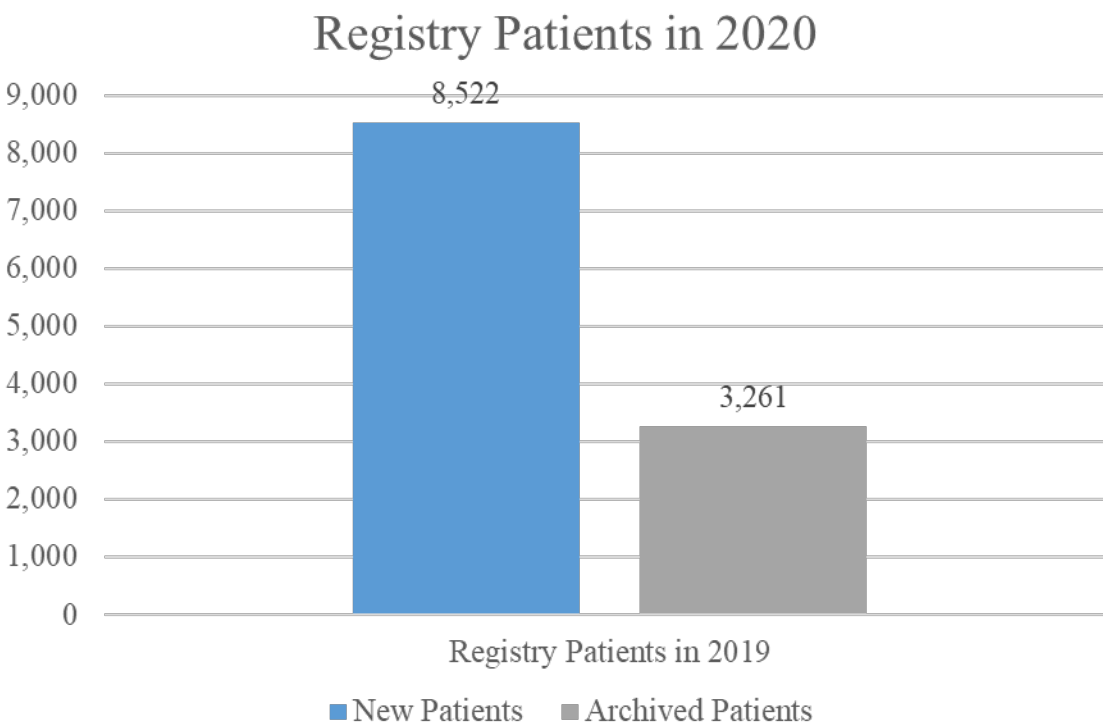


Table 12. Total forms received by type and classification

Total Forms Received by Type and Classification 10/1/2010 – 12/31/2020											
	COMB	LW	MPOA	DNR	POST	SS	MHAD	EREG	MISC	VNO	REVO
Forms Received	37,546	8,004	21,892	29,694	20,374	1,111	2	4,145	1,363	0	19
RR Forms	31,909	6,554	18,219	23,390	13,675	709	2	4,061	800	0	13
NRR Forms	5,637	1,450	3,673	6,304	6,699	402	0	84	563	0	6

Figure 9. Total forms received by type

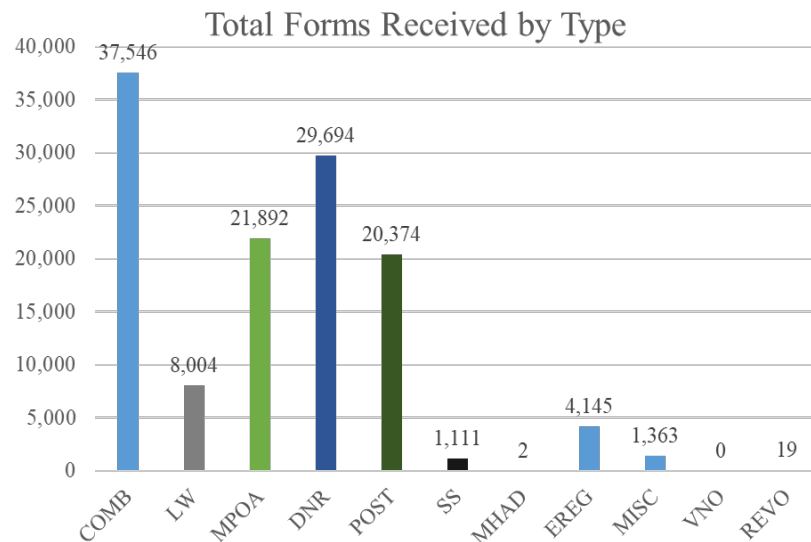
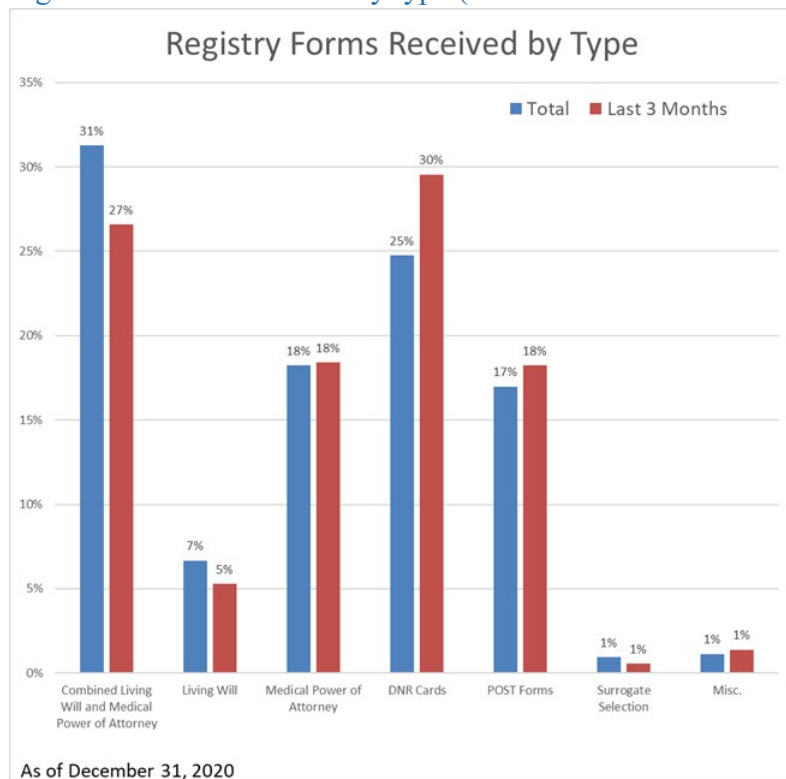


Figure 10. Forms received by type (total and last 3 month comparison)*



**Figure does not display data for MHAD (2), EREG (4,145), or REVO (19)*

Table 13. Forms received by type and classification in 2020

Forms Received by Form Type and Classification in 2020											
	COMB	LW	MPOA	DNR	POST	SS	MHAD	EREG	MISC	VNO	REVO
Forms Received	3,156	619	2,237	3,864	1,961	78	2	759	126	0	11
RR Forms	2,663	402	1,614	3,334	1,433	40	2	753	53	0	6
NRR Forms	493	217	623	530	528	38	0	6	73	0	5

Figure 11. Forms received by type in 2020

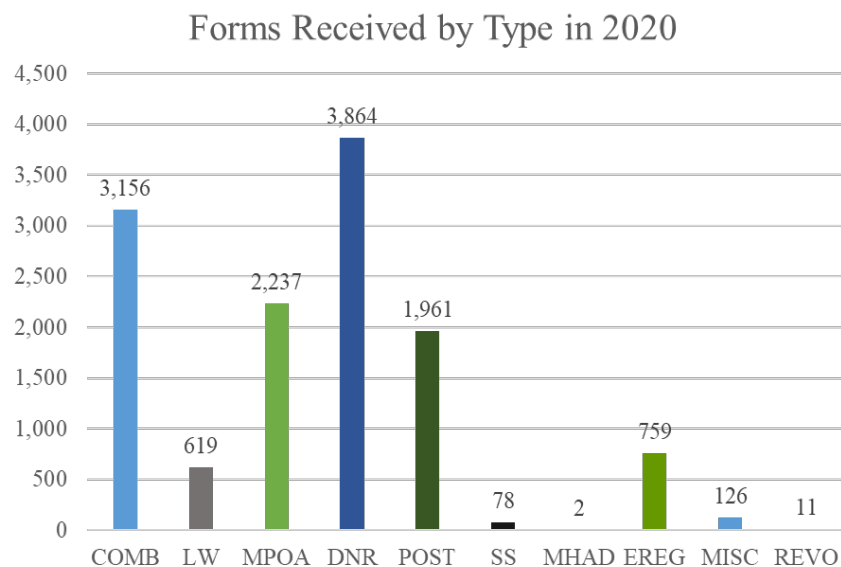
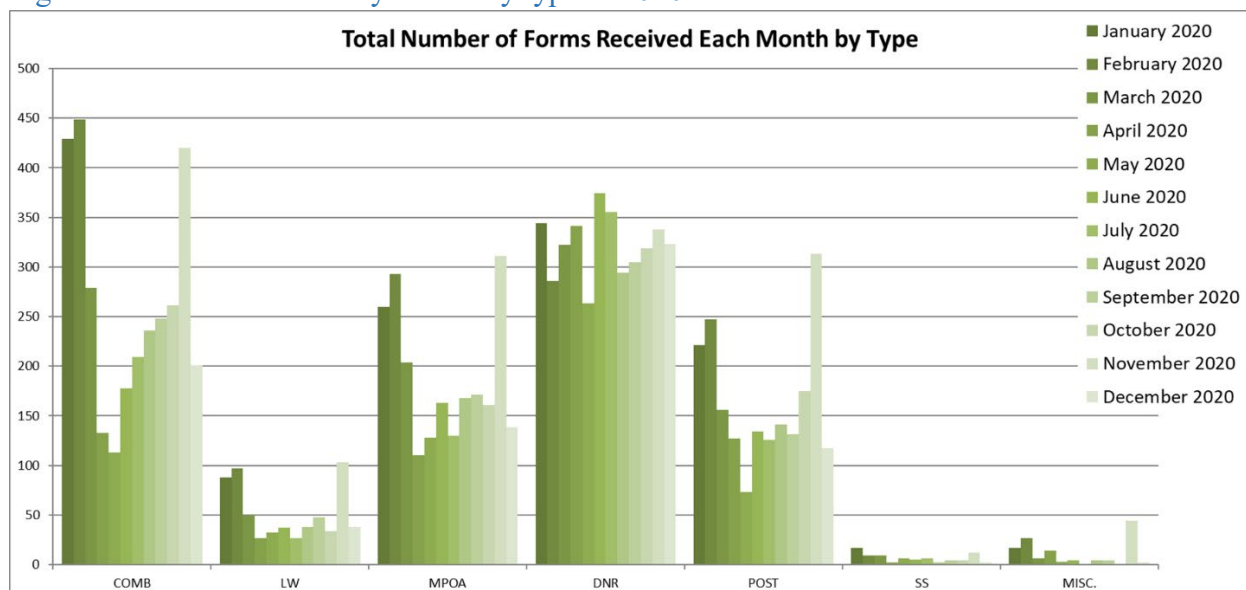


Figure 12. Forms received by month by type in 2020



*Figure 12 does not display data for MHAD (2), EREG (759), or REVO (11)

Figure 13. Forms received by month in 2020

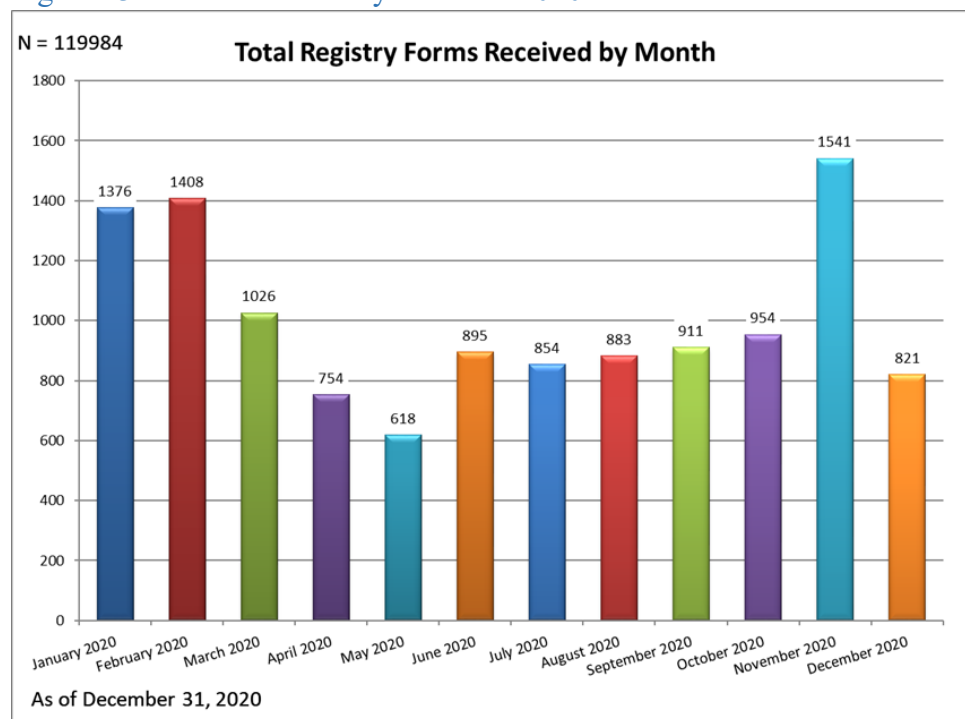
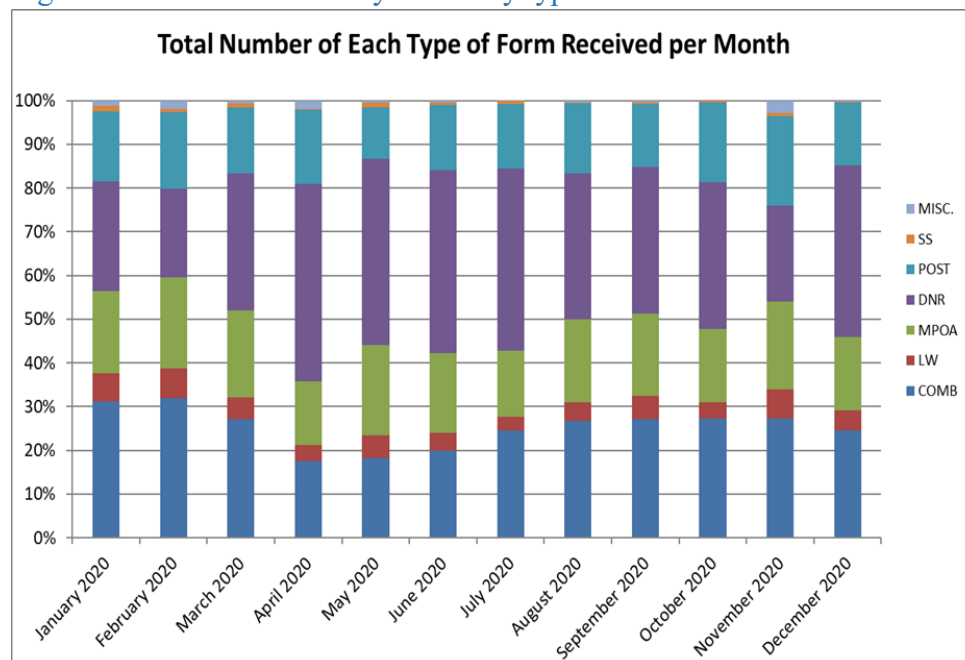


Figure 14. Forms received by month by type in 2020



*Figures 13 and 14 do not display data for MHAD (2), EREG (759), or REVO (11)

Figure 15. POST forms received by month in 2020

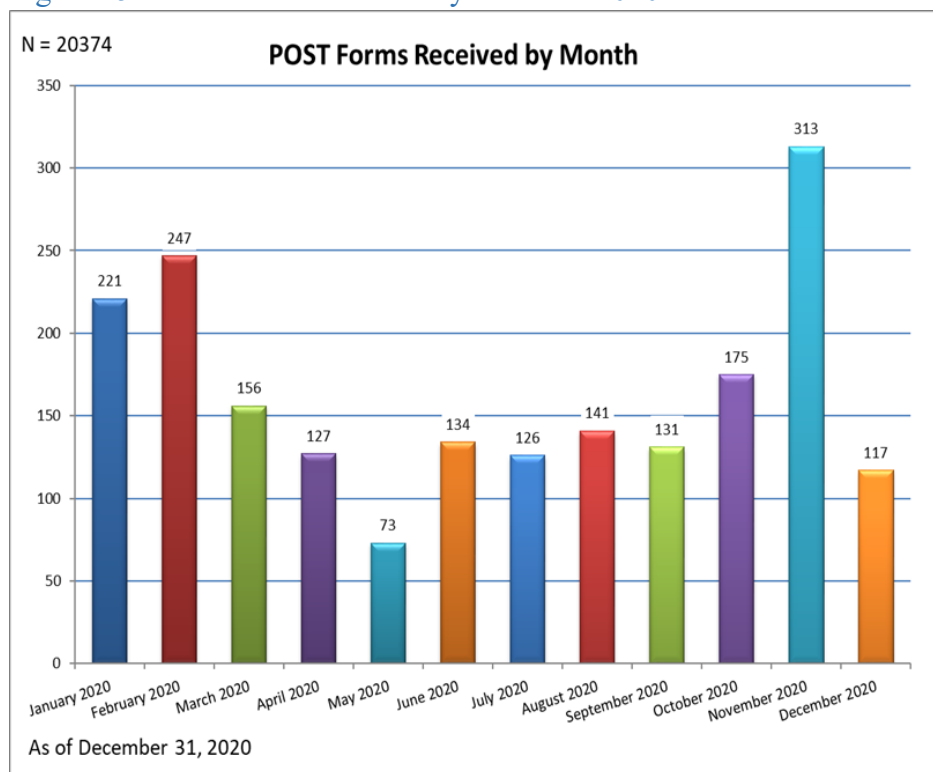


Figure 16. POST forms vs DNR cards received by month in 2020

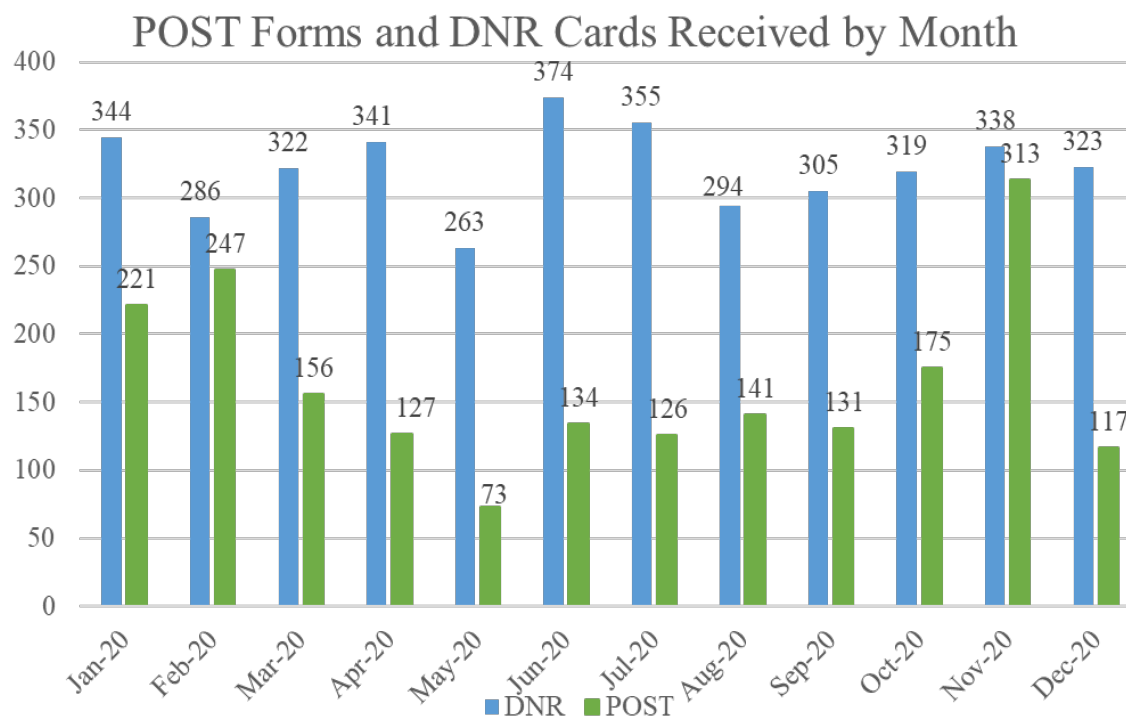


Figure 17. RR vs NRR forms received by month in 2020

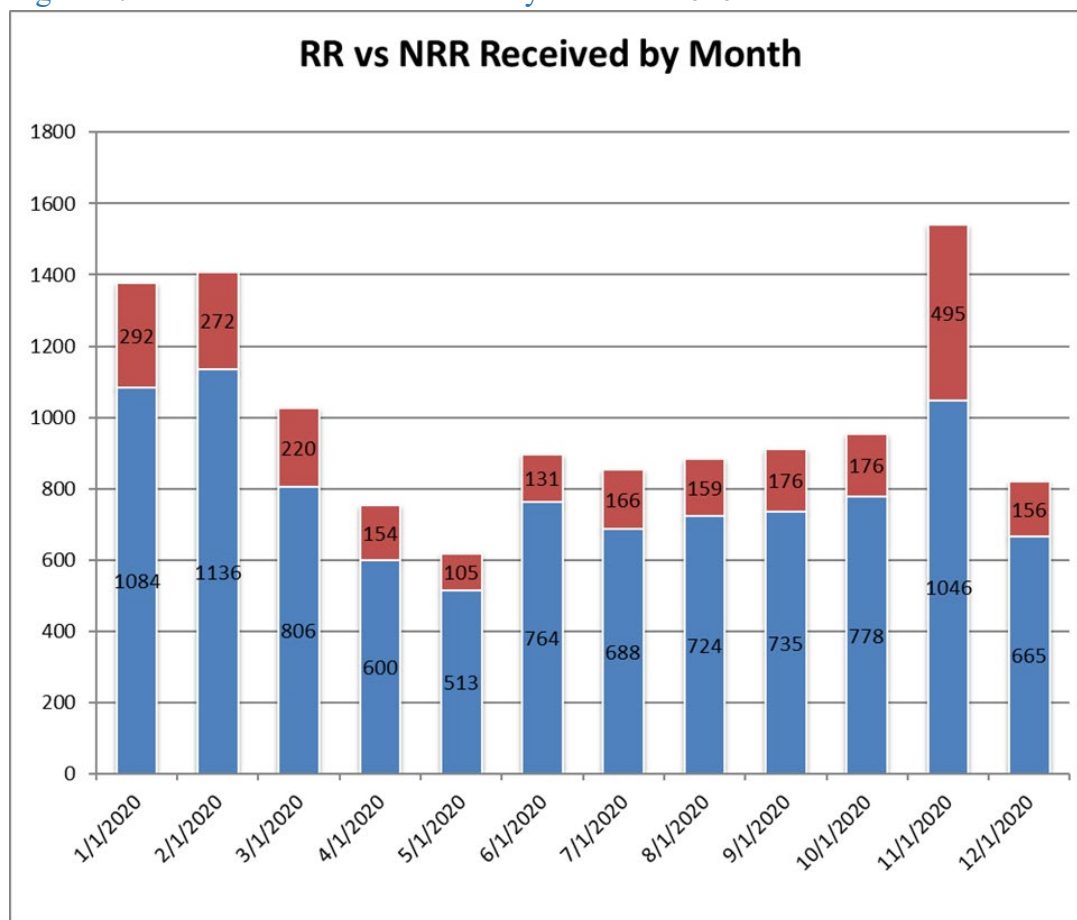


Figure 18. RR vs NRR forms received by type in 2020

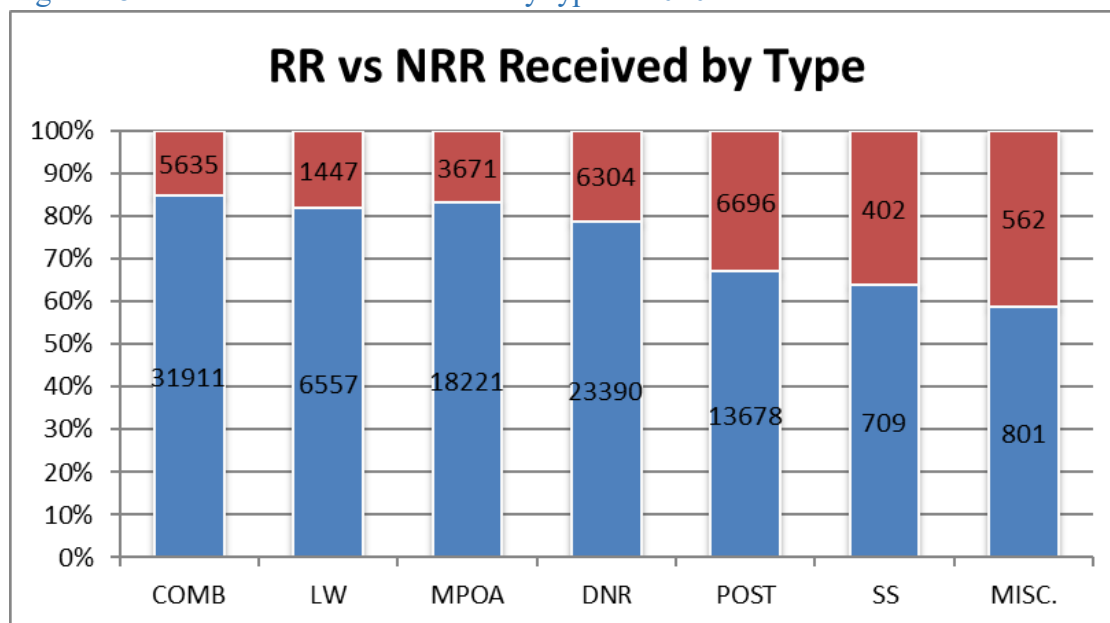


Figure 19. 2020 by the numbers: WV Center for End-of-Life Care

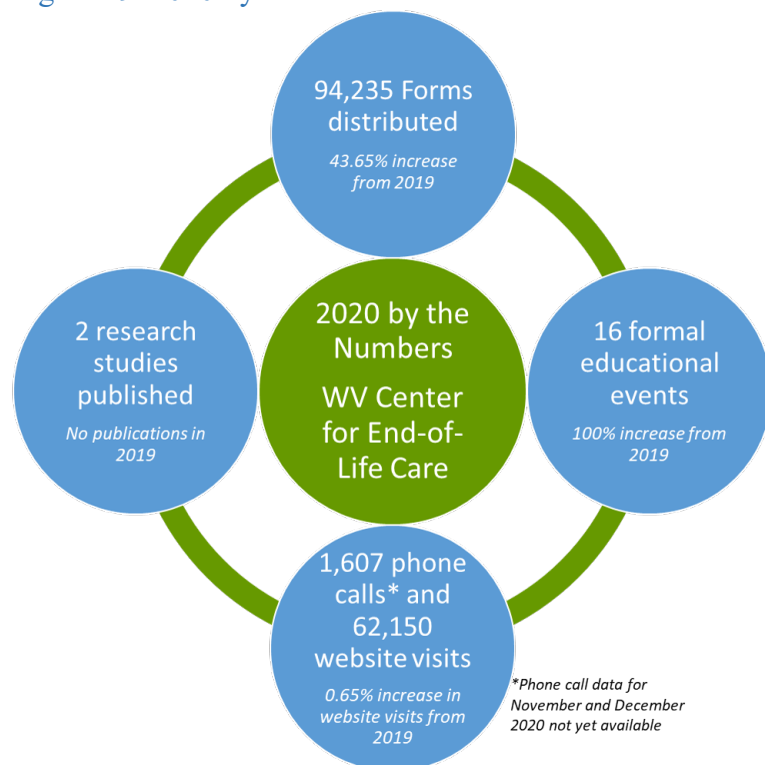
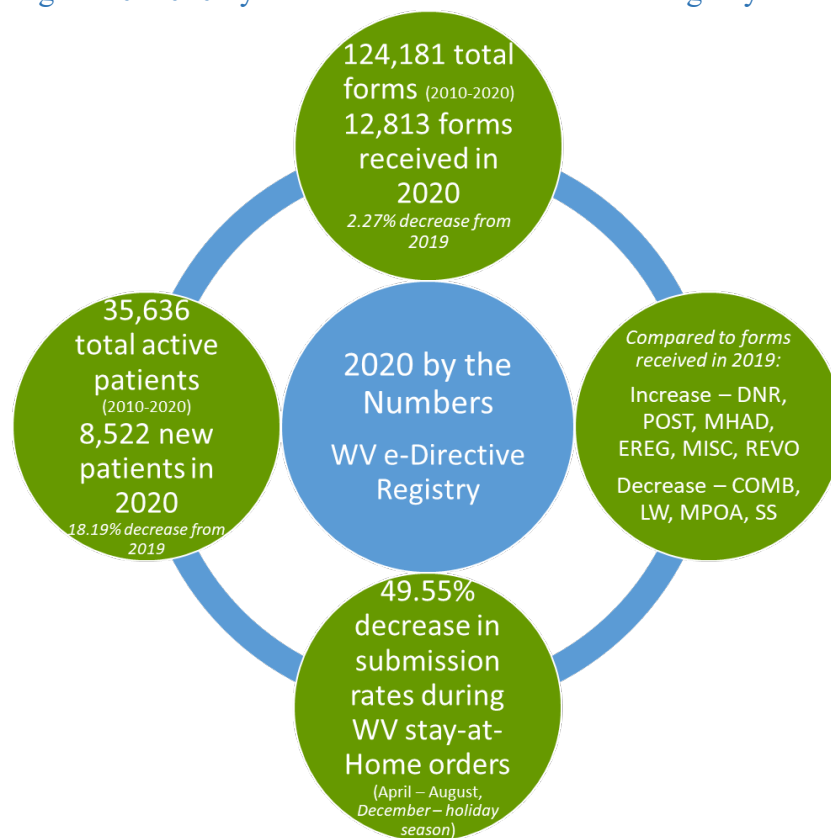


Figure 20. 2020 by the numbers: WV e-Directive Registry



Educational Events and Outreach Opportunities

Summary

In order to increase awareness related to advance care planning and to continue educating health care providers and patients, the Center offers multiple educational and outreach opportunities. The majority, if not all, of these events are offered at no charge for attendees. The purpose of these events is to continue addressing the imperative need to begin advance care planning and equip health care providers and patients with information to confidently approach this process. All events specifically including information or education on the POST form are reviewed by the National POLST. These events have been reported to be invaluable resources for health care providers and patients based on feedback in post-event evaluations.

During 2020, 16 different educational events and outreach opportunities were offered to both health care providers and outreach opportunities. These events were all in compliance with social distancing precautions and COVID-19 requirements. All presentations utilized virtual presentation and communication methods. Due to the uncertainty surrounding COVID-19 and the increased awareness on health care decisions, Danielle Funk, MS was determined to participate in as many educational and outreach opportunities as possible to allow West Virginians access to the information they need for advance care planning.

Table 14. WVCEOLC Educational Events and Outreach Opportunities in 2020

2020 Educational and Outreach Opportunities (continued on additional page)			
Event Date	Event Name <i>Type</i>	Presenter(s)	Number of Attendees
1/22/2020	WVU OLLI, “Advance Care Planning and the WV e-Directive Registry” <i>Community educational presentation</i>	Danielle Funk	32
1/22/2020	CAMC Geriatrics Luncheon <i>Professional educational presentation</i>	Danielle Funk	33
2/7/2020	WVU HIIM, “Registries in Healthcare” course <i>College educational guest lecturer</i>	Danielle Funk	40
3/10/2020	WVU HIIM, “Registries in Healthcare” course <i>College educational guest lecturer</i>	Danielle Funk	40
7/23/2020	WVU OLLI, “Advance Care Planning and the WV e-Directive Registry” <i>Community educational presentation</i>	Danielle Funk	32
8/5/2020	WV Adult Protective Services Workers <i>Professional educational presentation</i>	Danielle Funk and Dr. Alvin Moss	127
9/22/2020	WVU Tech, “Death and Dying” course <i>College educational guest lecturer</i>	Danielle Funk	22
9/23/2020	WVU OLLI, “A Taste of OLLI” <i>Community educational introduction presentation</i>	Danielle Funk	<i>Free live-stream video publicly available</i>
10/2/2020	Senior Monongalians, “Senior Expo” <i>Community resource distribution event</i>	Danielle Funk	200
10/15/2020	WVU OLLI, “Advance Care Planning, the WV e-Directive Registry, and COVID-19” <i>Community educational presentation</i>	Danielle Funk	16

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10/18/2020	WV Geriatric Society webinar, “Advance Care Planning in WV” <i>Professional education presentation</i>	Danielle Funk	
10/20/2020	Policy Counsel for the Minnesota Medical Association – Development of a POLST Registry <i>Professional collaboration meeting</i>	Danielle Funk	1 – <i>Information to be shared with stakeholders</i>
10/20/2020	WDTV Full News Package, Discussing research publication “How COVID-19 Changed Advance Care Planning in WV” <i>Community informational outreach opportunity</i>	Danielle Funk	<i>News package shared publicly via television and internet formats</i>
11/3/2020	North Memorial Health Clinic – Minnesota, Advance Care Planning during COVID-19 <i>Professional collaboration and exchange of education</i>	Danielle Funk	3 – <i>Information to be shared with the North Memorial Health Clinic Social Work Team</i>
11/18/2020	WV Geriatric Society webinar – “How COVID-19 Changed Advance Care Planning in WV” <i>Professional educational presentation</i>	Danielle Funk	

wvendoflife.org Public Website

The Center’s website, wvendoflife.org, received significant usage during 2020 with 62,150 website visits. The website was created in February 2002 to provide publicly available information, forms, and resources to both health care providers and patients. The website is managed by both the Center’s Program Manager and the WVU IT Department. The website now has a page with information on how individuals can give back to the Center including financial donations and non-financial support: <http://wvendoflife.org/support-the-center/>.

2020 WV Center for End-of-Life Care and e-Directive Registry Personnel

The Center's highly revered student worker, Ashley Boyce, resigned from her position in January to advance her career in other employment but continued to volunteer with the Center through April. Danielle Funk, MS was promoted from Program Assistant II to Program manager in February 2020. The collaboration between the West Virginia University (WVU) Division of Health Informatics and Information Management (HIIM) established in 2019 continued to be a fruitful experience for the HIIM volunteers and beneficial work assistance for the Center with four different HIIM volunteers during 2020. One additional volunteer served at the Center from the WVU Department of Dental Hygiene undergraduate major.

2020 Personnel List

Volunteers: Erin Wamsley, Angela Bohon, Ashley Boyce (January 2020 – April 2020), Abigail Charles, and Danish Waseem

Student Worker: Ashley Boyce (through January 2020)

Database Manager: Atticus Speis, MS

Program Manager: Danielle Funk, MS

Director: Alvin H. Moss, MD, FACP, FAAHPM

2020 WV Center for End-of-Life Care Finances

In 2020, approximately \$60,500 was required for operational costs of the Center and approximately \$97,000 was required for personnel expenses. The Center is currently operating at its bare minimum financially which has negatively impacted the number of Center personnel and severely limited the amount of opportunities the Center can offer to the community. The personnel budget of \$97,000 was divided amongst two full-time employees (salaries, fringes, and benefits) and one student worker (through January 2020). A breakdown of the operational budget during the 2020 calendar year is listed below.

Operational costs:

\$25,500	Registry upgrade to a custom application system (payment 1 of 2)
\$19,410	Secure hosting charges of Registry data with PHI protection and liability
\$6,020	Printing charges for medical orders and Registry mass mailings
\$5,345	Postage charges
\$2,075	Secure electronic faxing services with PHI protection
\$1,100	Computer supplies
\$945	Telephone charges for the toll-free line
\$100	Ink charges for printing of resources other than medical orders and Registry mass mailings

The Center personnel were grateful for the \$2,000 gift from EPIC to help cover costs related to COVID-19. Danielle Funk, MS continues to apply for additional funding. In previous years, the operational and personnel budget for the Center was \$550,000; the budget during the 2020 calendar year was \$157,500. Because the Center's budget is approximately 3.5 times lower than the ideal budget needed, the opportunities and resources provided by the Center must also be one-third of the ideal situation. The upmost gratitude is extended to the individuals in the WVU HSC finance office and at WVU Foundation, specifically Loreta Mascoli and Anne Bolyard, for their continued efforts in finding additional funding for the Center.

Information on how individuals can give back to the Center and help support the Center's mission both financially and otherwise can be found at: <http://wvendlife.org/support-the-center/>.

2020 WV e-Directive Registry on WVHIN

The WV e-Directive Registry is available 24/7 to treating health care providers through the West Virginia Health Information Network (WVHIN). WVHIN has a new, easy to use unified landing page (ULP) which shows all the patient's information including if any documents are available for them through the Registry. In 2020, over 1,460 accounts were authorized to access the WV e-Directive Registry through WVHIN's ULP.

Currently, Berkeley Medical Center, Blue Ridge Internal Medicine Inc., CAMC Health Network, Cabell Huntington Hospital, Camden Clark Medical Center, Davis Medical Center, Elmcroft, Fresenius Family Care, Genesis, Grant Memorial Hospital Clinics, Marshall Family Medicine, Mercer Medical Group, Ohio Valley Physicians, Pleasant Valley Hospital, Princeton Community Hospital, Ruby Memorial Hospital, St. Mary's Medical Center, Stonerise Healthcare,

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United Hospital Center, United Physicians Care, United Health Associates, University Healthcare Physicians, Valley Health, West Virginia University Health System locations, Winchester Medical Center, WVU Hospitals, and WVU Cancer Institute are among some of the current authorized users of the ULP.

Congratulations to the top health care facilities which used WVHIN's ULP to search forms on the WV e-Directive Registry in 2020:

1. **Ruby Memorial Hospital Care Management**
2. Davis Medical Center (*Tied for 2nd*)
2. Thomas Memorial Hospital (*Tied for 2nd*)

Also, congratulations to the top individual users of the WV e-Directive Registry through WVHIN's ULP in 2020.

1. **Katherine Prescott, Ruby Memorial Hospital Care Management**
2. Maggie Phillips, Thomas Memorial Hospital
3. Elizabeth Grime, Davis Medical Center

Well done to Ruby Memorial Hospital Care Management used the ULP to find Registry forms 7 times more than both facilities tied for second place! Kudos to Katie for using the ULP for Registry forms 4 times more than the second place user!

To become a member of WVHIN and have 24/7 access to your patient's forms on the e-Directive Registry, email info@wvhin.org or dcfunk@hsc.wvu.edu.