

2019



West Virginia Center for
End-of-Life Care

Annual Report

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Executive Summary

2019 was a transitional year for the WV Center for End-of-Life Care (Center). The Center began the year without managerial leadership but with the support of one dedicated student worker 20 hours per week. In February 2019, Danielle Funk, MS, was hired as the Program Assistant II and transitioned smoothly into this role based on her previous experience as a student worker for the Center during her undergraduate education. In April, Atticus Speis, MS, was hired as the Database Manager for the e-Directive Registry (Registry) through the Center to fill the void in database-specific personnel following the resignation of the previous Database Manager, Evan Falkenstine, MS, in December 2018. Also, the position of the Database Technician I was eliminated based on decisions from West Virginia University (WVU), thus resulting in Timothy Woody's, MS, employment at the Center being terminated. During all of the personnel transitions, Danielle Funk coordinated with the WVU Division of Health Informatics and Information Management (HIIM) to offer volunteer opportunities to undergraduate HIIM students with interest in health care registries. Two HIIM volunteers worked on the Registry through the Center during 2019. This proved to be a beneficial collaboration in assisting with the work load and allowing HIIM students to meet their Division-required volunteer hours in an applicable setting.

The Center's coordination efforts expanded beyond personnel in multiple different areas of education and outreach. Danielle Funk collaborated with the West Virginia Cancer Coalition: Mountains of Hope to create the WV Cancer Plan for 2021-2025. Previously, the Center was involved with the WV Cancer Plan for 2016-2020. Educational presentations were offered for attendees of the National Active and Retired Federal Employees – Morgantown Chapter, the WVUTech "Death and Dying" course, the Senior Monongalians "Senior Expo," and the WV Emergency Medical Services: Prehospital Healthcare Ethics ECHO. In addition, the Center was featured through Danielle Funk's presentation during the WVU "Making a Difference – Compassionate Care for the Elderly" professional conference. Education for health care providers specifically related to the WV Physician Orders for Scope of Treatment (POST) form was offered formally as part of a two-part webinar series, "Completing the POST Form." In total, a minimum of 446 individuals received formal educational and outreach opportunities offered by the Center. An electronic format for education was also created in 2019 called "Enlightened EOLC" to provide information through both email listservs and social media.

Finally, the Center continued to meet the goals of providing education, coordination, and resources related to advance care planning throughout the state and beyond. These efforts were further reinforced by the Center undergoing a regular review resulting in the re-endorsement of the WV POST program by the National POLST. The Center has been endorsed by the National POLST since 2013 and maintains its designation as a mature, endorsed program. The Center continued to serve the state of WV by focusing on high-quality and accurate information and resources provided by a team of dedicated personnel with attitudes to help individuals with their advance care planning journey. The operating structure of the Registry, still recognized as a national leader for registries of its kind, is in dire need of an upgrade to maintain its current level of operability with the continual increase in form submissions. Serious conversations for future

upgrades to the Registry began during 2019 and will continue throughout 2020. 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, Kelley Grove, and Victoria Thomas, for their continued support and commitment to help the Center serve as a necessary resource the state of WV and the Registry serve both health care providers and patients with their health care wishes. 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. 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 listed here and those whom were acknowledged in spirit for continuing to help support the Center's mission and improve advance care planning practices in West Virginia.

As 2019 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. An upgrade to the Registry operating system continues to be a top goal for 2020 as well. Please enjoy the 2019 Annual Report. For any questions, please contact Danielle Funk.

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, WV e-Directive Registry
dcfunk@hsc.wvu.edu

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 in order 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 (POLST stands for Physician Orders for Life-Sustaining Treatment; the Center found the language of “life-sustaining” to be contradictory with the purpose of the POST form). 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 patients 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.

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

Terms in this Report:

Forms distributed – Forms sent from the WV Center for End-of-Life Care to health with advance care planning. Forms and resources are sent free of charge. Forms are either mailed or downloaded from the Center's website (wvendoflife.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, Living Will, Combined Medical Power of Attorney and Living Will, Mental Health Advance Directive (since 2019), frequently asked questions and forms packet, surrogate selection, 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 wvendoflife.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 help their patients with advance care planning

Table 1. Total form distribution by form type

Total Forms Distributed 04/01/2002 – 12/31/2019: 1,145,206	
DNR cards	319,014
POST forms	620,783
Advance Directives	205,409

Table 2. Form distribution by form type in 2019

2019 Monthly Review: 65,600												
	January 2019	February 2019	March 2019	April 2019	May 2019	June 2019	July 2019	August 2019	September 2019	October 2019	November 2019	December 2019
DNR cards	2,114	1,199	1,704	1,149	1,114	1,490	1,705	1,165	1,890	1,685	2,000	920
POST forms	1,724	2,564	3,050	2,975	2,741	2,695	2,615	2,995	3,292	3,395	2,750	2,489
Advance Directives	1,587	1,557	1,737	1,321	1,340	1,082	885	949	910	1,064	977	890

Figure 1. Total form distribution by form type

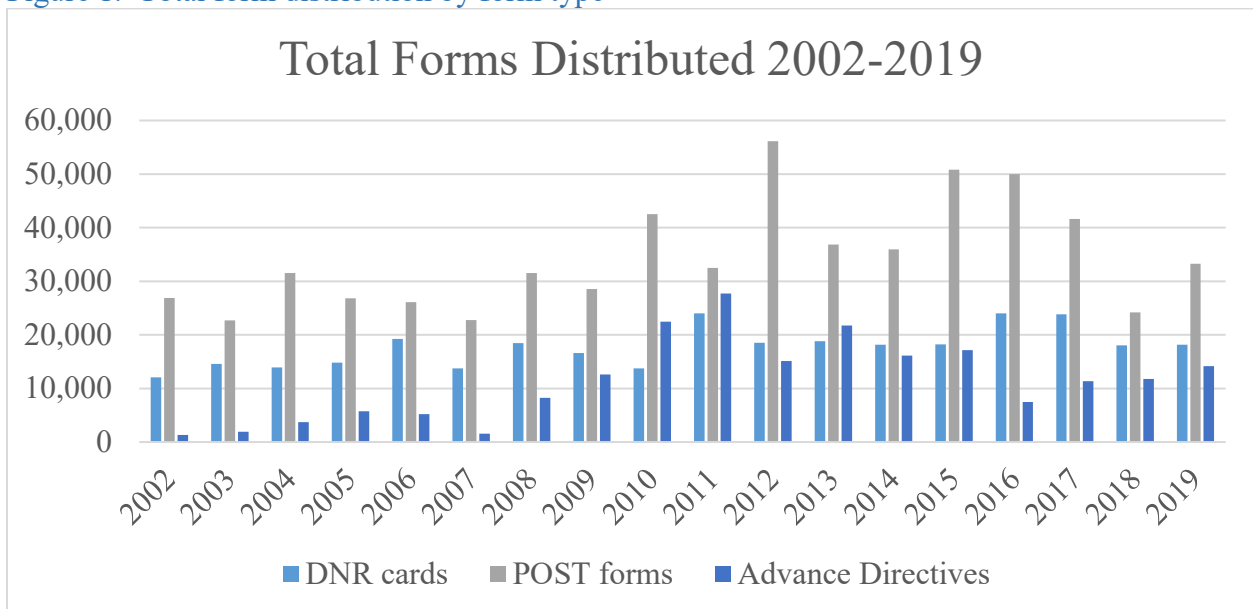


Figure 2. Total form distribution by form type in 2014-2019 (6 year trend)

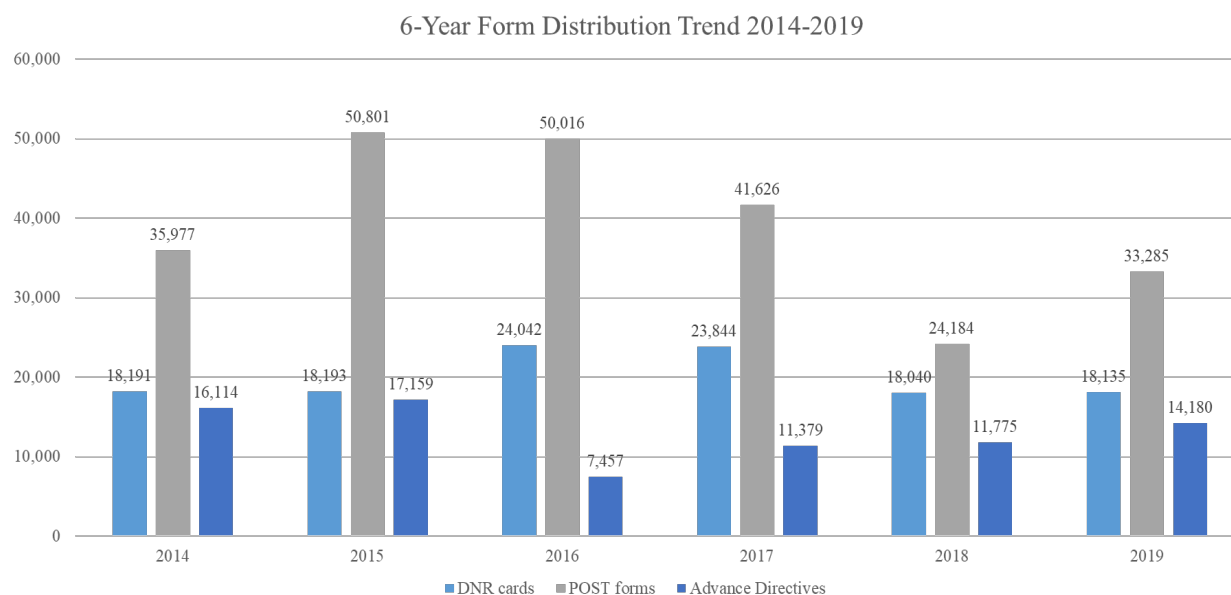


Table 3. Total communication by communication type

Total Communication 04/01/2002 – 12/31/2019: 706,428	
Calls on the toll-free 877-209-8086 line	34,042
Website visits	672,206

Table 4. Communication by communication type in 2019

2019 Communication Review	
Calls on the toll-free 877-209-8086 line	1,775
Website visits	61,848

Table 5. Monthly communication by communication type in 2019

2019 Monthly Review												
	January 2019	February 2019	March 2019	April 2019	May 2019	June 2019	July 2019	August 2019	September 2019	October 2019	November 2019	December 2019
Calls on the toll-free 877-209-8086 line	203	222	181	163	172	132	156	176	141	134	115*	95
Website visits	6,265	6,194	6,136	5,006	5,098	4,928	4,862	5,258	4,746	4,750	4,192	4,413

*Table 5: November 2019 Phone call count was not reported. 115 is the estimate based on the average number of calls per month between October and December 2019

Figure 3. Total communication by communication type

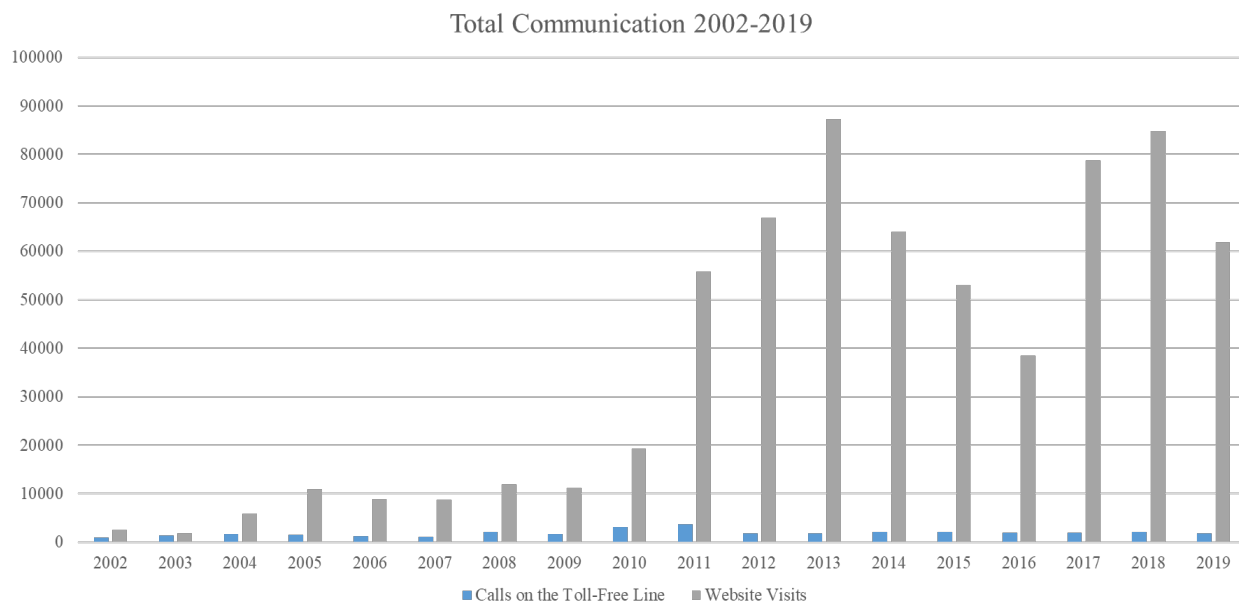
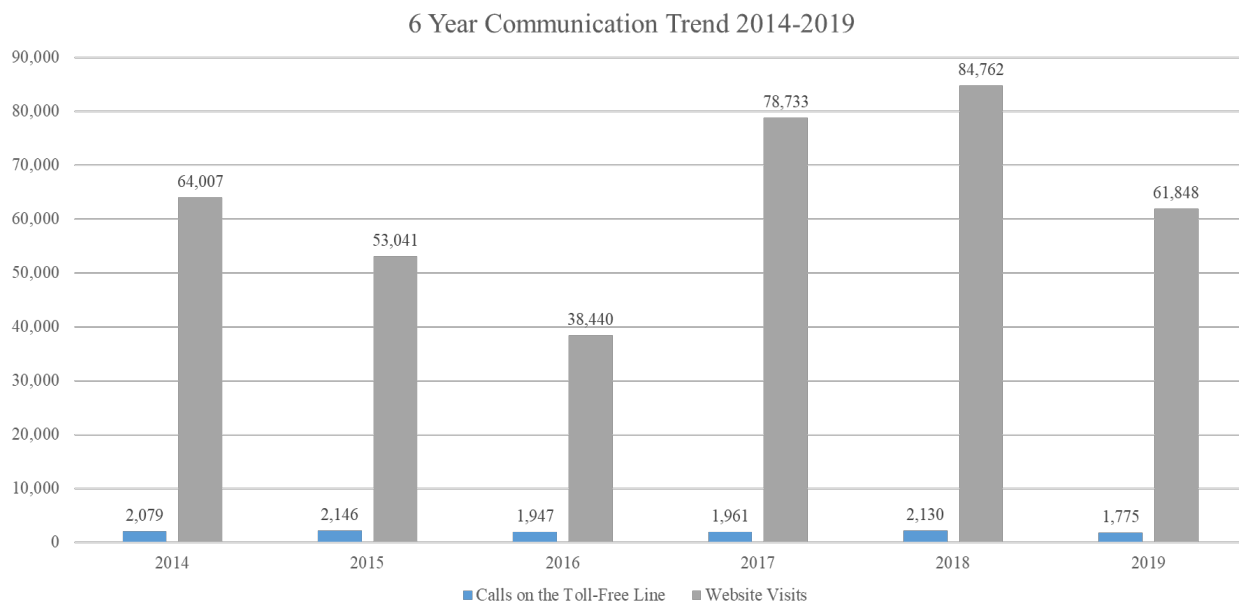


Figure 4. Total communication by communication type in 2014-2019 (6 year trend)



Annual Reports: WV e-Directive Registry

As of December 31, 2019

Terms in 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 (opt-in) 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 meets 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

Table 6. Total forms received by classification

Cumulative Registry Form Review and Totals (10/1/2010 – 12/31/2019)	
Forms Received	111,337
Active Forms	56,941
Archived Forms	54,396
RR Forms	89,032
NRR Forms	22,305

Table 7. Forms received by classification in 2019

2019 Registry Form Review and Totals	
Forms Received	13,110
Active Forms	8,660
Archived Forms	4,450
RR Forms	10,351
NRR Forms	2,759

Table 8. Total patient totals by classification

Cumulative Registry Patient Review and Totals (10/1/2010 – 12/31/2019)	
All Patients	82,569
Archived Patients	39,182

Table 9. Patient totals by classification in 2019

2019 Registry Patient Review and Totals	
New Patients	10,417
Archived Patients	3,480

Figure 5. Total forms received by classification 2002-2019

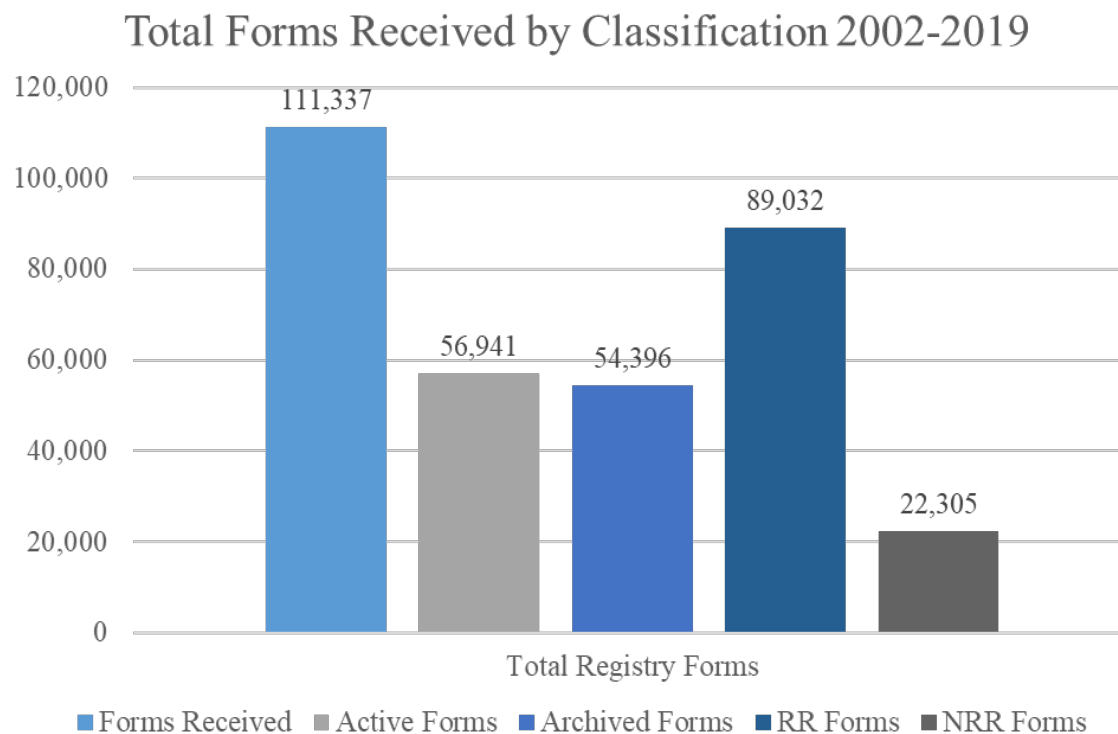


Figure 6. Forms received by classification in 2019

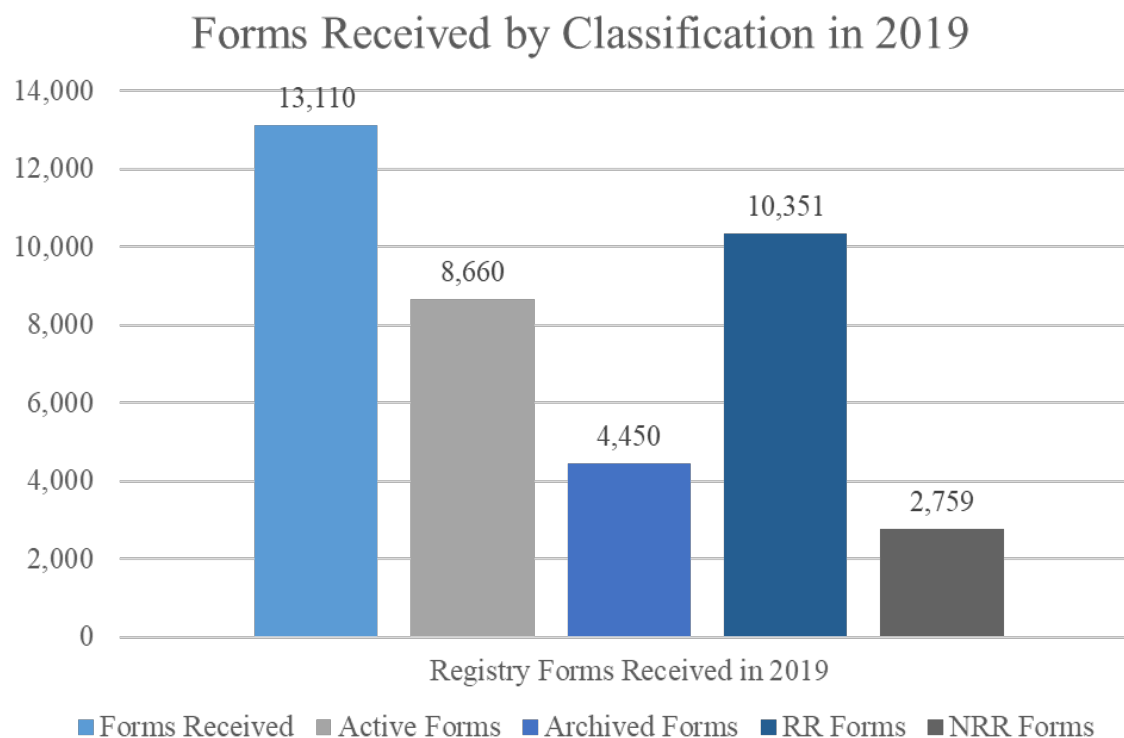


Figure 7. Total Registry patients 2002-2019

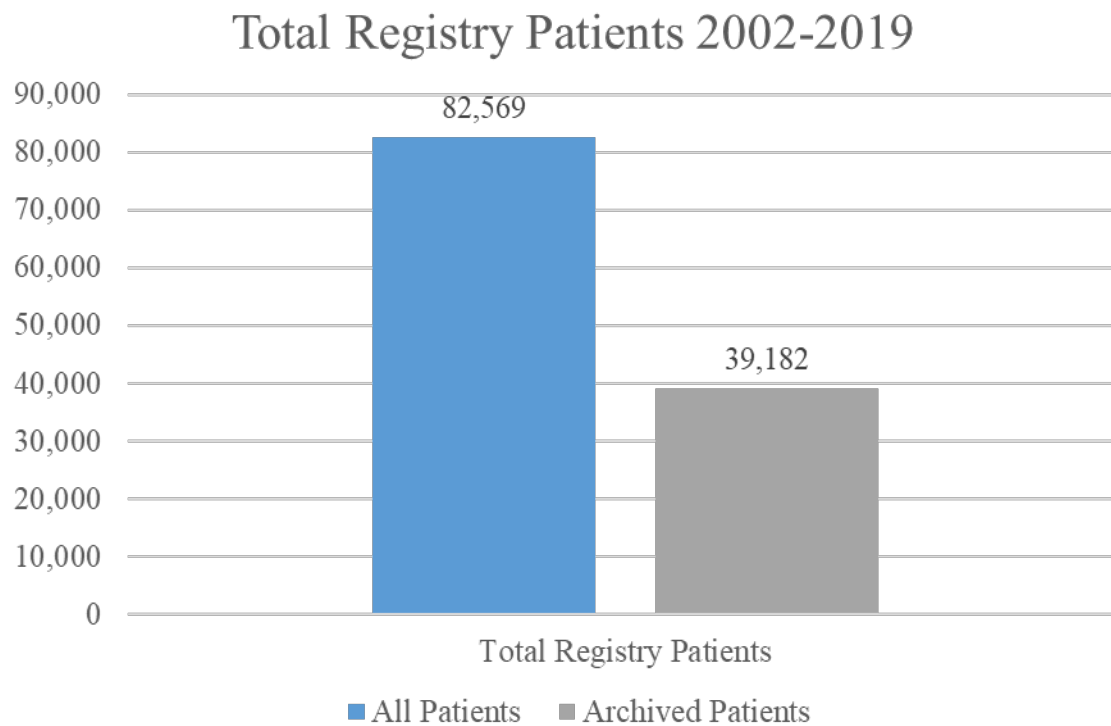


Figure 8. Registry patients in 2019

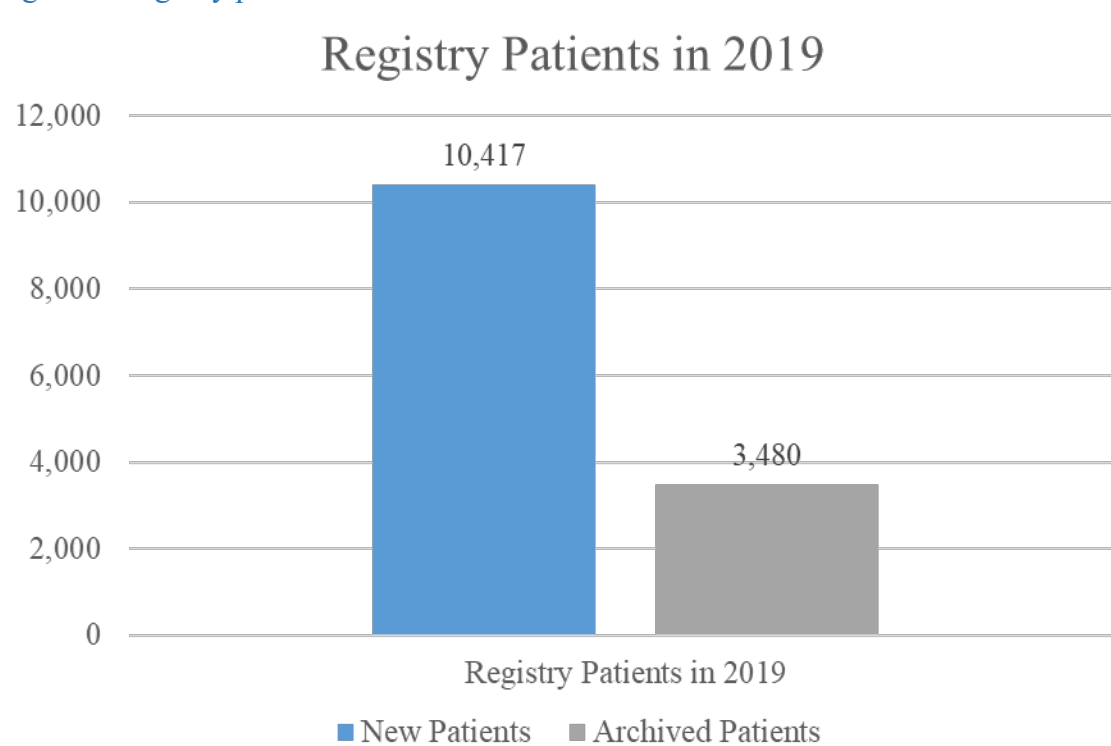


Table 10. Total forms received by type and classification

Total Forms Received by Type and Classification 10/1/2010 – 12/31/2019											
	COMB	LW	MPOA	DNR	POST	SS	MHAD	EREG	MISC	VNO	REVO
Forms Received	34,390	7,385	19,655	25,830	18,413	1,033	0	3,386	1,237	0	8
RR Forms	29,246	6,152	16,605	20,056	12,242	669	0	3,308	747	0	7
NRR Forms	5,144	1,233	3,050	5,774	6,171	364	0	78	490	0	1

Figure 9. Total forms received by type

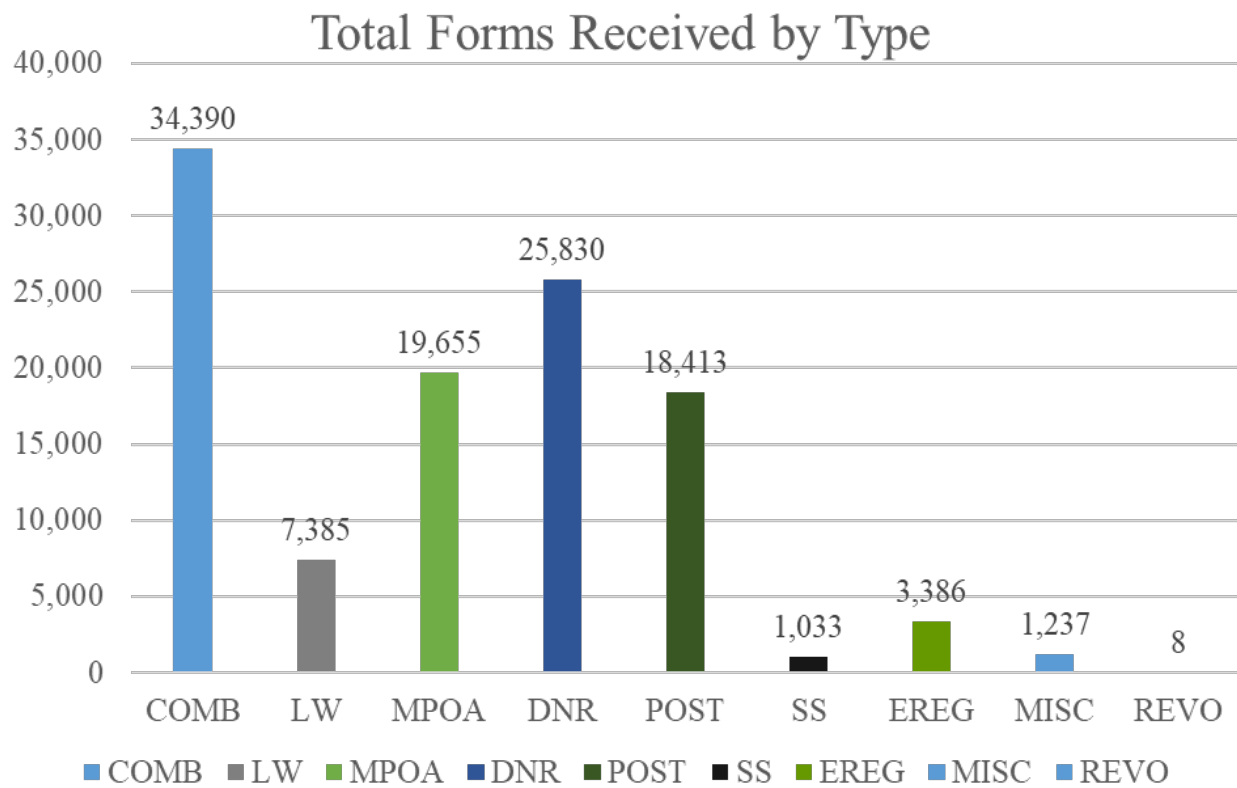
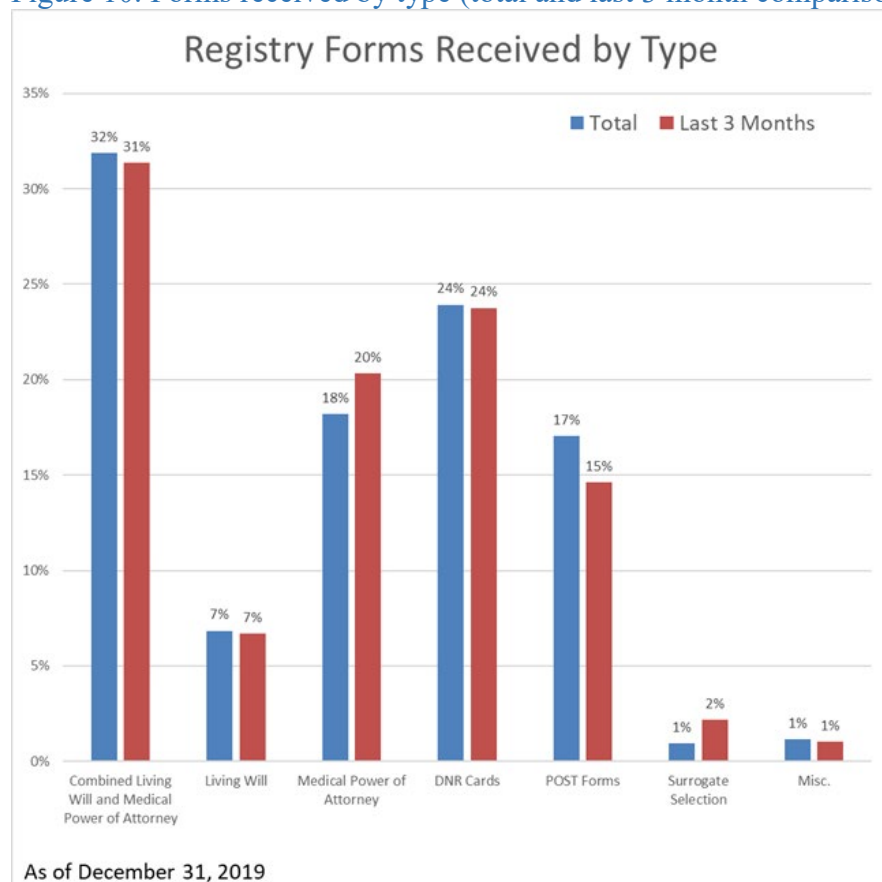
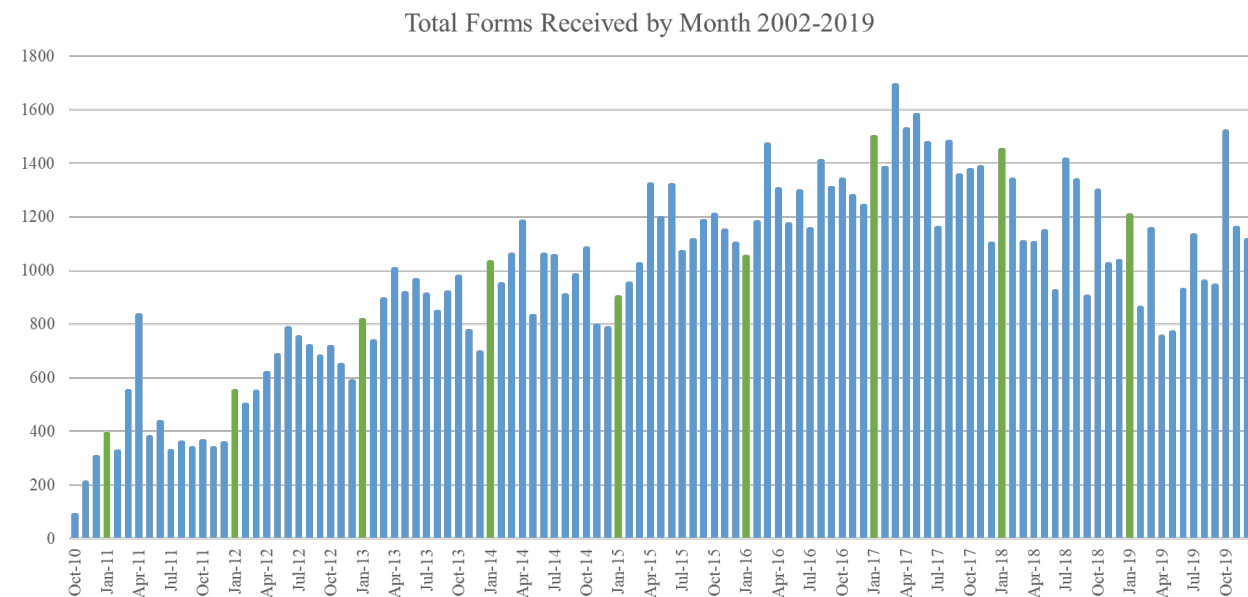


Figure 10. Forms received by type (total and last 3 month comparison)



**Figure does not display data for MHAD (0), EREG (3,386), or REVO (8)*

Figure 11. Total forms received by month



**Figure 11 monthly totals do not include EREG or REVO totals. Green bars indicate first month of each year*

Table 11. Forms received by type and classification in 2019

Forms Received by Form Type and Classification in 2019											
	COMB	LW	MPOA	DNR	POST	SS	MHAD	ERE	MISC	VNO	REVO
Forms Received	4,315	821	2,534	2,670	1,906	155	0	595	106	0	8
RR Forms	3,584	649	1,971	2,065	1,379	49	0	588	59	0	7
NRR Forms	731	172	563	605	527	106	0	7	47	0	1

Figure 12. Forms received by type in 2019

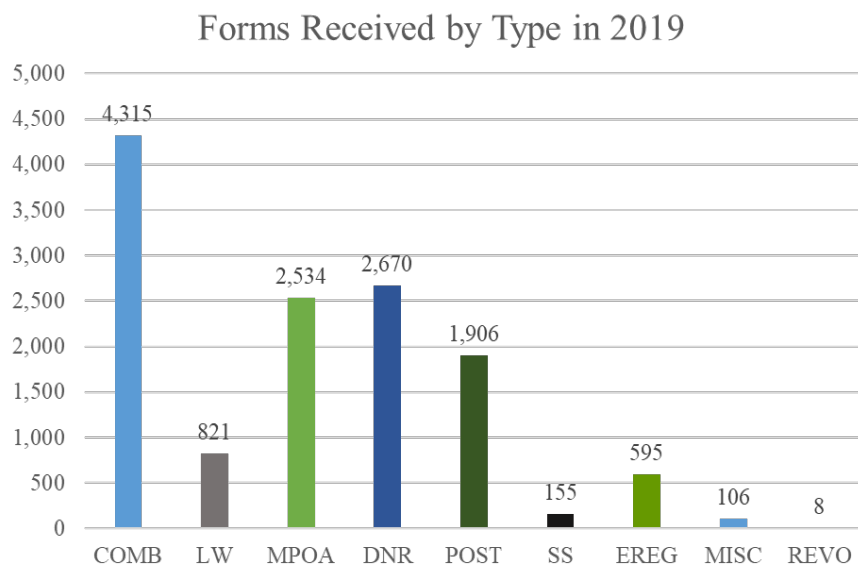
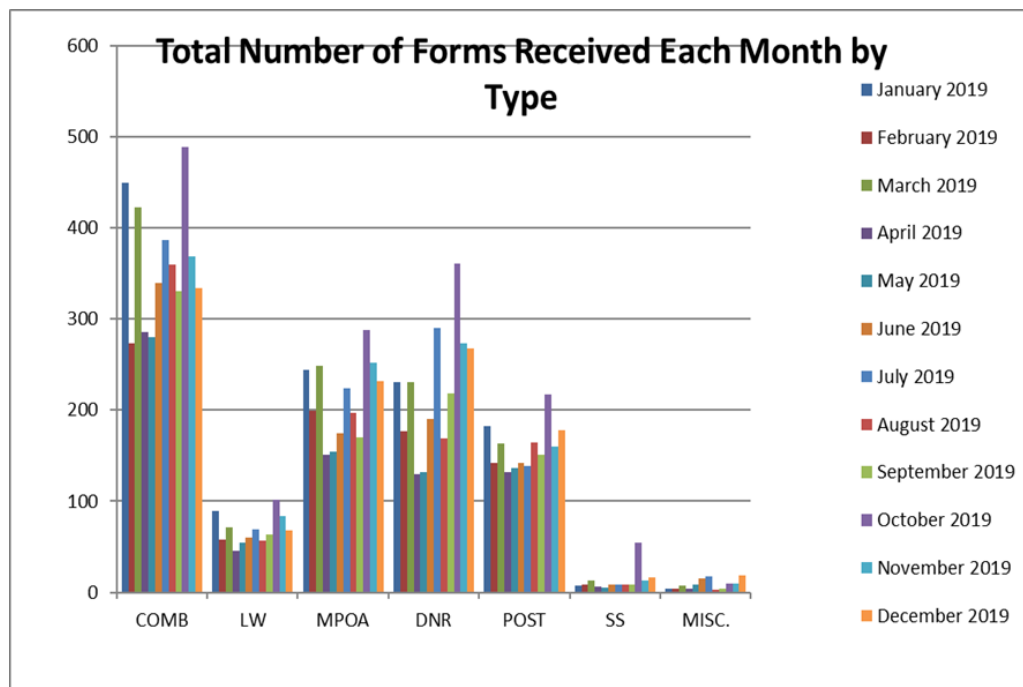


Figure 13. Forms received by month by type in 2019



*Figure 13 does not display data for MHAD (0), EREG (3,386), or REVO (8)

Figure 14. Forms received by month in 2019

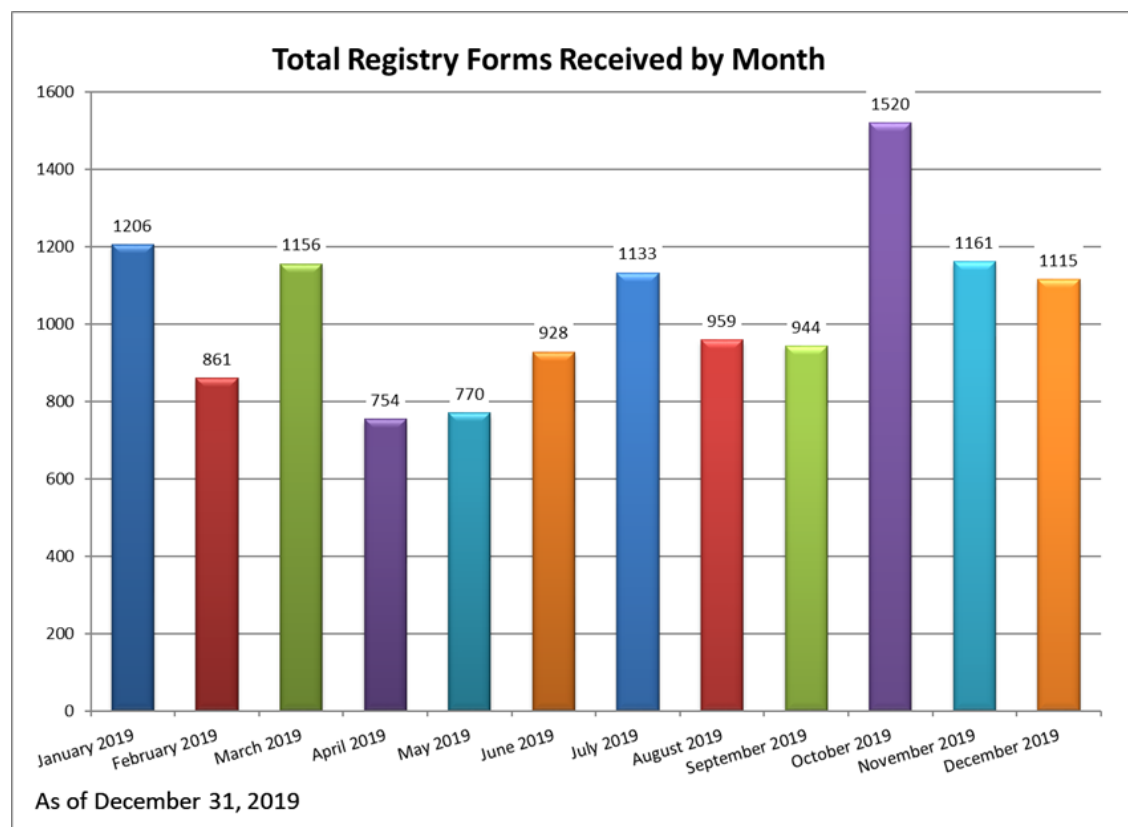
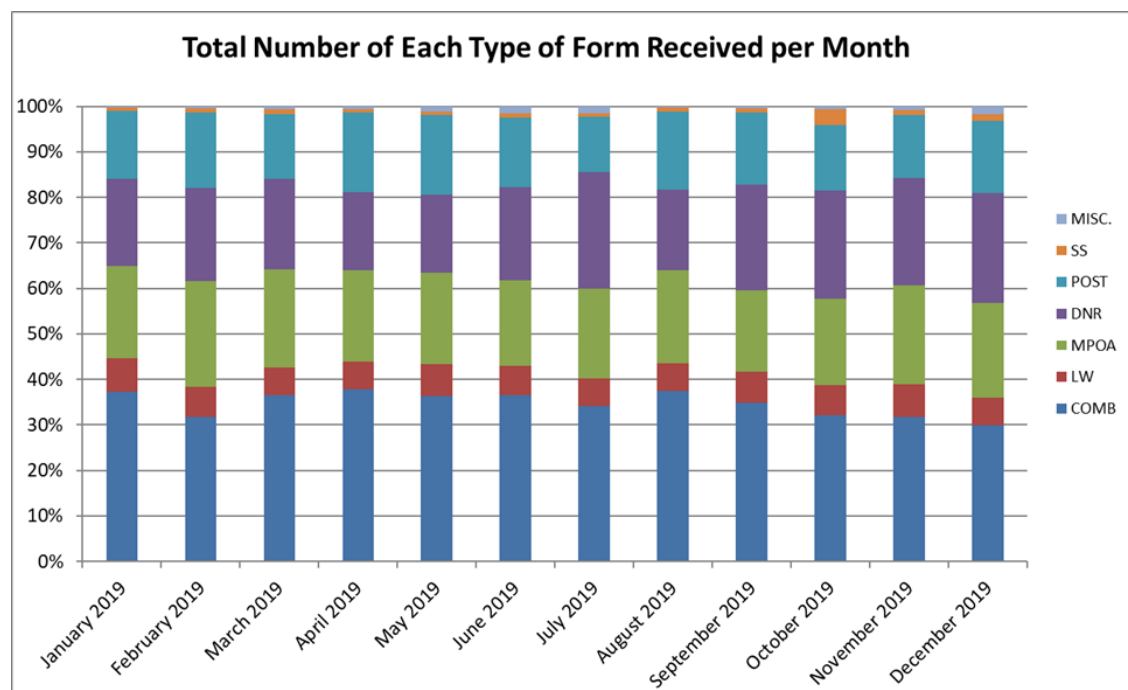


Figure 15. Forms received by month by type in 2019



*Figures 14 and 15 do not display data for MHAD (0), EREG (3,386), or REVO (8)

Figure 16. POST forms received by month in 2019

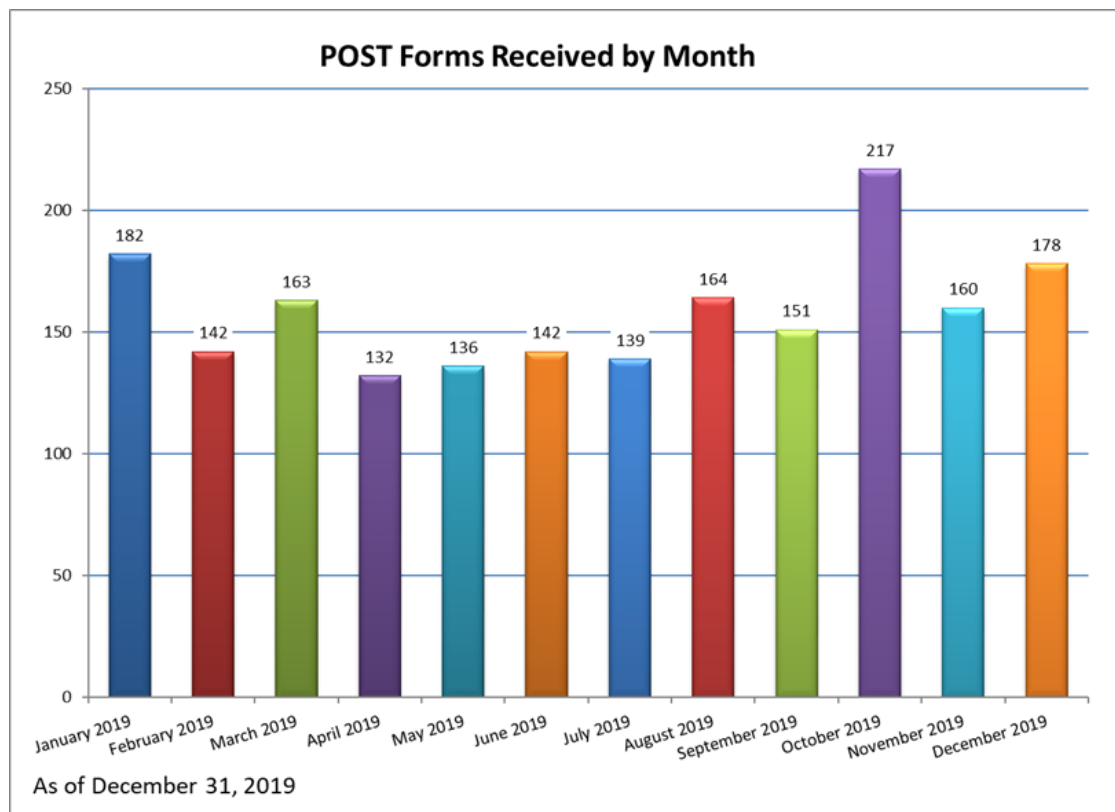


Figure 17. POST forms vs DNR cards received by month in 2019

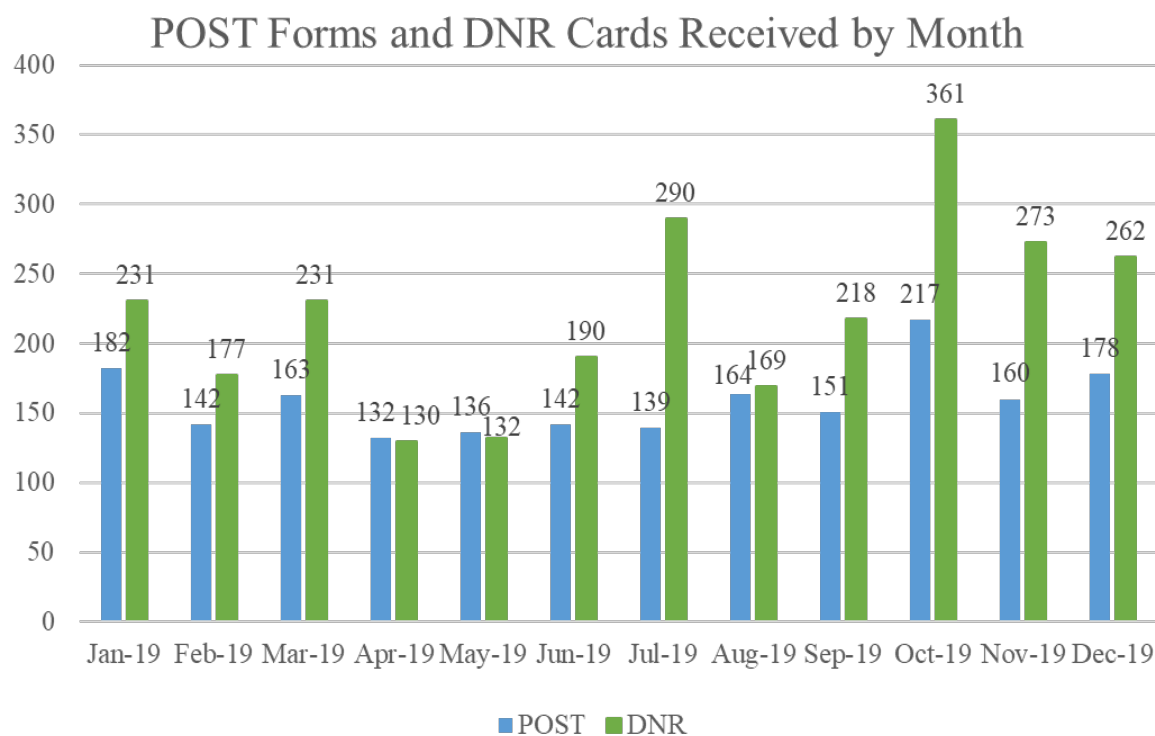


Figure 18. RR vs NRR forms received by month in 2019

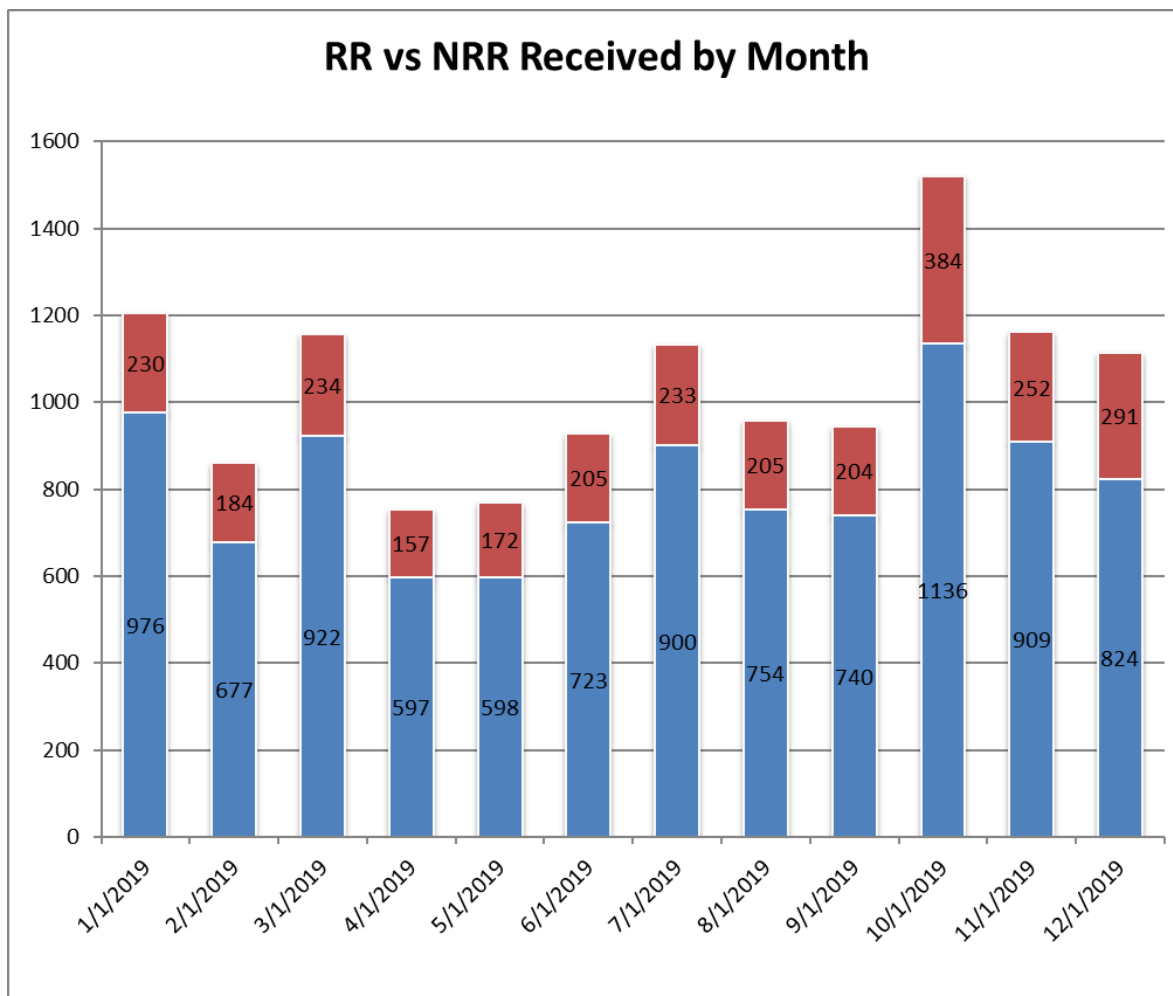


Figure 19. RR vs NRR forms received by type in 2019

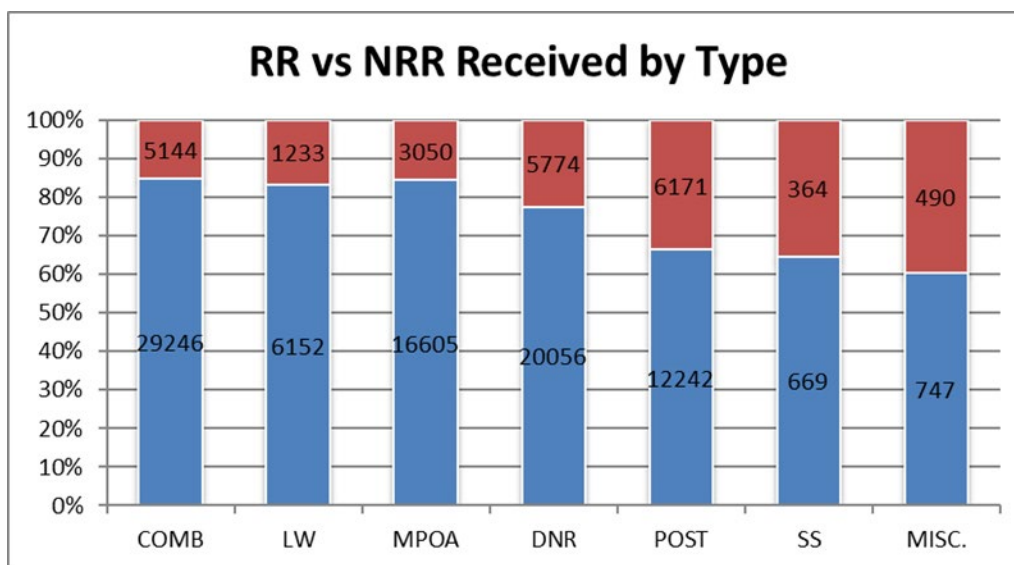


Figure 20. 2019 by the numbers: WV Center for End-of-Life Care

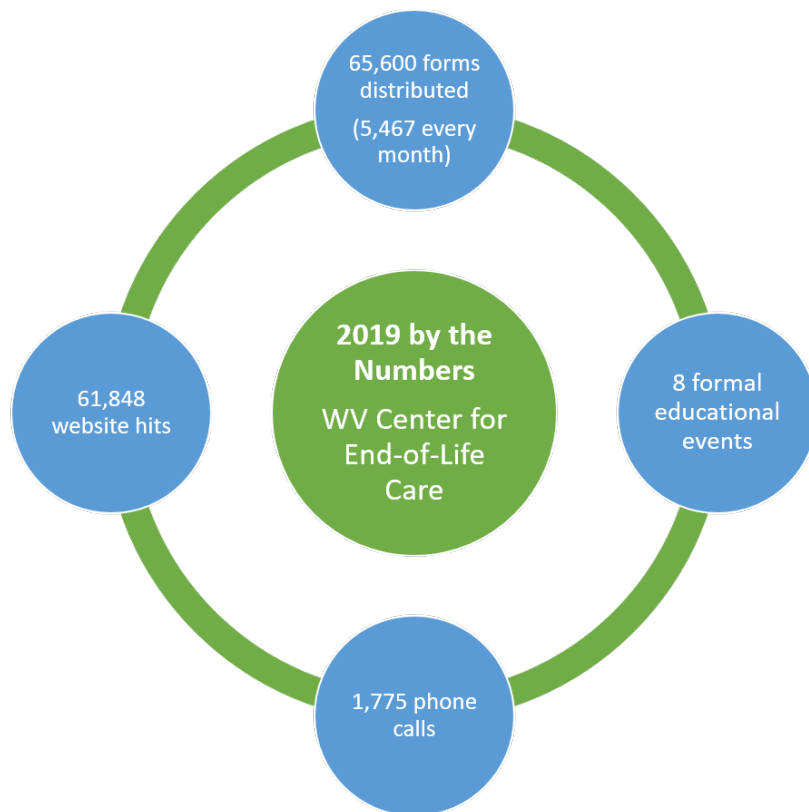
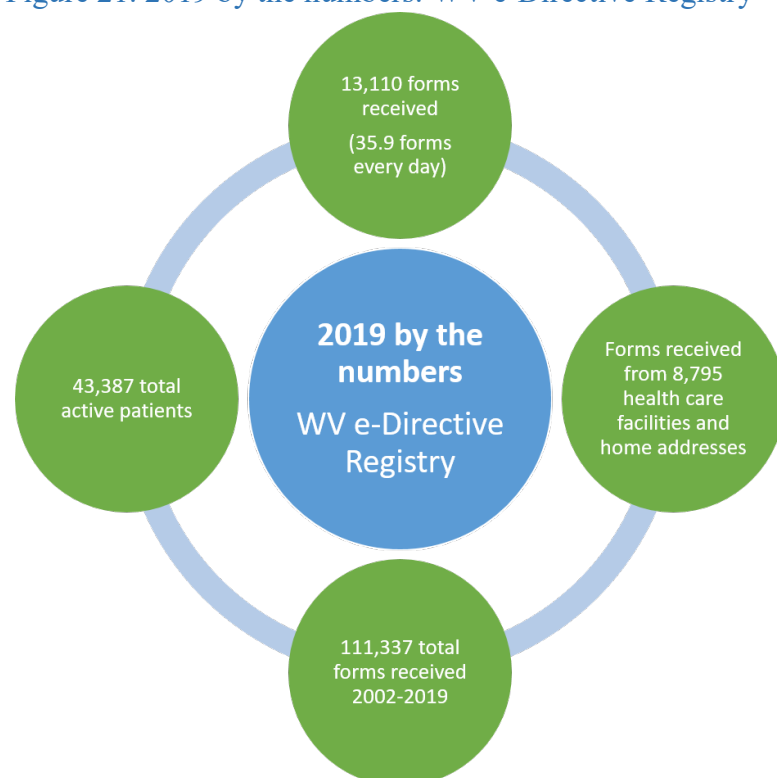


Figure 21. 2019 by the numbers: WV e-Directive Registry



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 2019, 7 different educational events and outreach opportunities were offered to both health care providers and outreach opportunities. In addition to the events (listed below in Table 9), a new subprogram, called “Enlightened EOLC,” began in 2019. Enlightened EOLC provided short weekly information related to advance care planning and frequently asked questions. This information was provided both by email through LISTSERVs and social media.

Table 12. WVCEOLC Educational Events and Outreach Opportunities in 2019

2019 Educational and Outreach Opportunities			
Event Date	Event Name <i>Type</i>	Presenter(s)	Number of Attendees
4/24/2019	“Ask the Office! Office Hours” <i>Open discussion, question and answer session</i>	Danielle Funk	NA – event was available through social media and office calls/emails
8/14/2019	National Active and Retired Federal Employees – Morgantown Chapter <i>Community educational presentation</i>	Danielle Funk	25
9/19/2019	WVU Tech, “Death and Dying” course <i>College educational guest lecturer</i>	Danielle Funk	19
9/26/2019	Senior Monongalians “Senior Expo” <i>Community information-based event</i>	Danielle Funk	175
9/30/2019	WVU “Making a Difference – Compassionate Care for the Elderly” <i>Professional conference presentation</i>	Danielle Funk	33
10/8/2019	“Completing the POST Form” webinar: Part 1: The Who, What, and Why of POST form Completion <i>Professional educational presentation</i>	Danielle Funk, Alvin Moss, Valerie Satkoske	96
10/22/2019	“Completing the POST Form” webinar: Part 2: The When, Where, and How of POST form Completion <i>Professional educational presentation</i>	Danielle Funk, Alvin Moss, Valerie Satkoske	65
11/21/2019	WV Emergency Medical Services, Prehospital Healthcare Ethics ECHO <i>Professional educational presentation</i>	Danielle Funk	≥ 33 <i>An official count of participants is not recorded. 33 people submitted evaluations following the presentation.</i>

wvendoflife.org Public Website

The Center’s website, wvendoflife.org, received significant usage during 2019 with 61,848 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.

2019 WV Center for End-of-Life Care and e-Directive Registry Personnel

Volunteers: Antonia Dunnigan and Monika Kuzmicki

Student Worker: Ashley Boyce

Database Technician I: Timothy Woody, MS

Database Manager: Atticus Speis, MS

Program Assistant II: Danielle Funk, MS

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