



West Virginia Center for End-of-Life Care

Annual Report: 2020

FAX 844-616-1415

www.wvendoflife.org

CALL 877-209-8086

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

2002: WV Legislature amended the Health Care Decision Act to include the Physician Orders for Scope of Treatment (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.

WV Center for End-of-Life Care Mission Statement

Established in 2002 by the WV Legislature, the West Virginia Center for End-of-Life Care 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.

2020: Notable Events

- A Registry upgrade begins in mid-2020 and is projected to end in 2021.
- Publication by Center staff of two peer-reviewed journal articles highlighting the unique contributions the Center and Registry are making to a national understanding of advance care planning
- COVID-19 influences record-breaking annual form distribution from the Center
- The Center participated in 100% more educational and outreach opportunities than 2019.
- The Center's services are heavily utilized. In 2020, there were 62,150 website hits excluding internet bots! The Center website averages over 5,000 hits per month in addition to approximately 200 phone calls per month to the Center's toll-free line.
- The Center received its first financial gift in many years. EPIC gifted the Center \$2,000 to help with COVID-19 expenses.
- The Center established a donation and support page to inform the public on how to give back to the Center: <http://wvendoflife.org/support-the-center/>

Terms in this report	Definition
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 (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, 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 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 help their patients with advance care planning

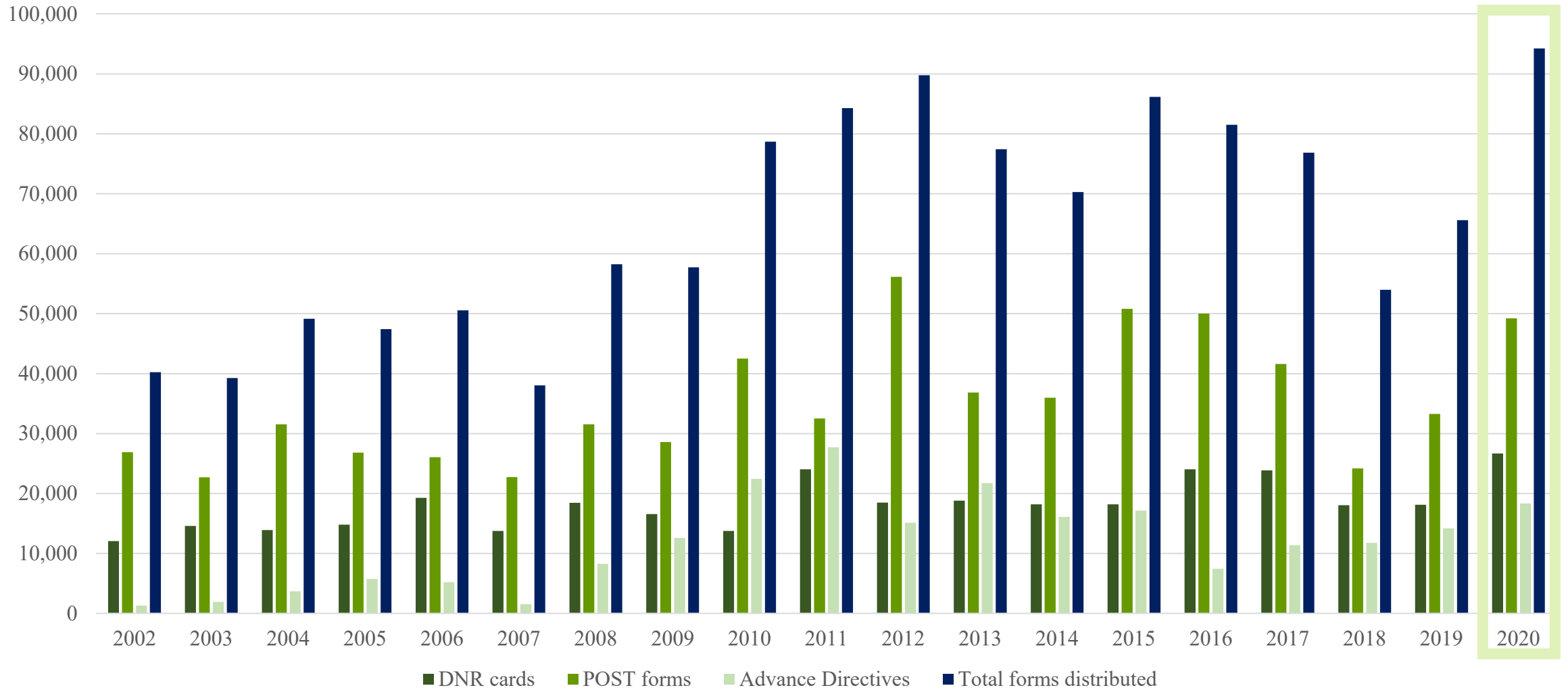
Total Forms Distributed 04/01/2002 – 12/31/2020: 1,261,099	
DNR cards	345,681
POST forms	669,993
Advance Directives	245,425

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)

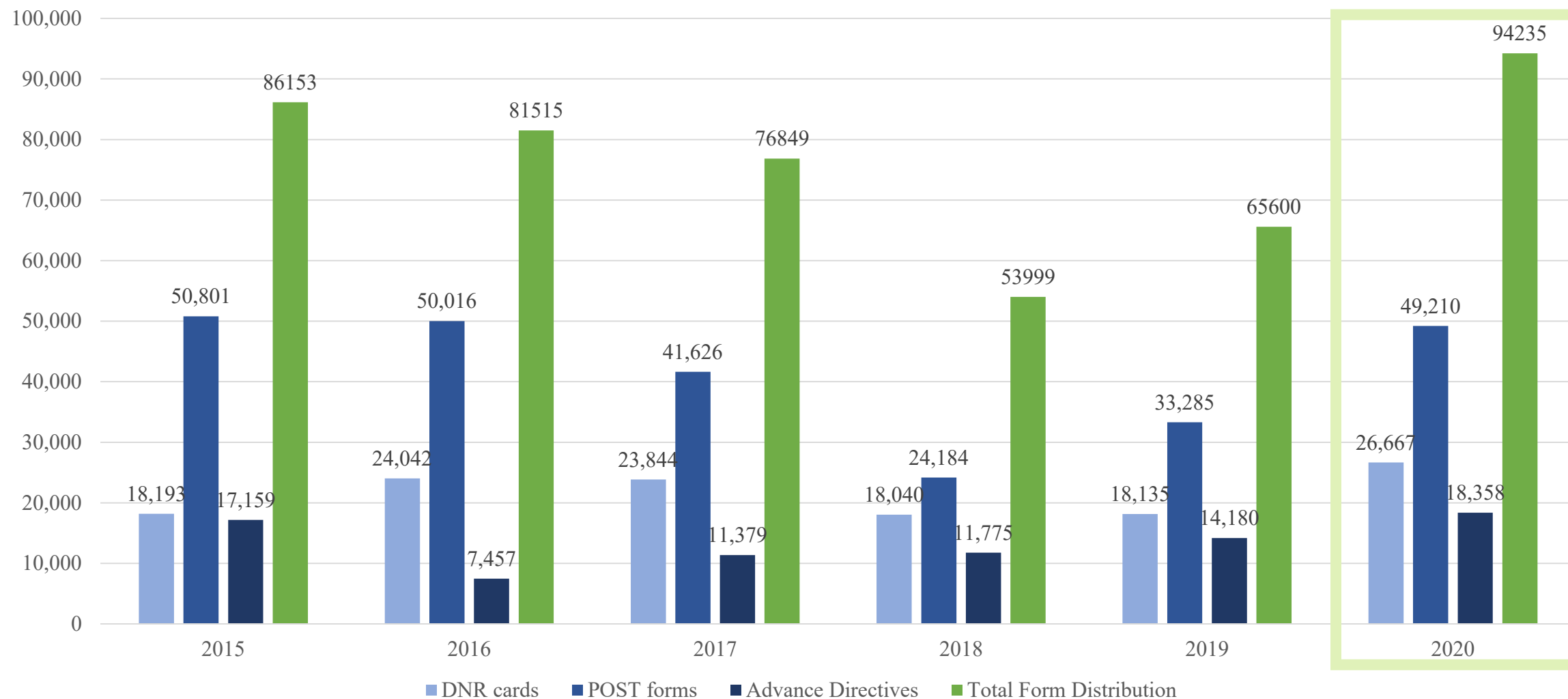
2020 Monthly Review: 94,235

	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

Total Forms Distributed by Form Type 2002-2020



6-Year Form Distribution Trend 2015-2020



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

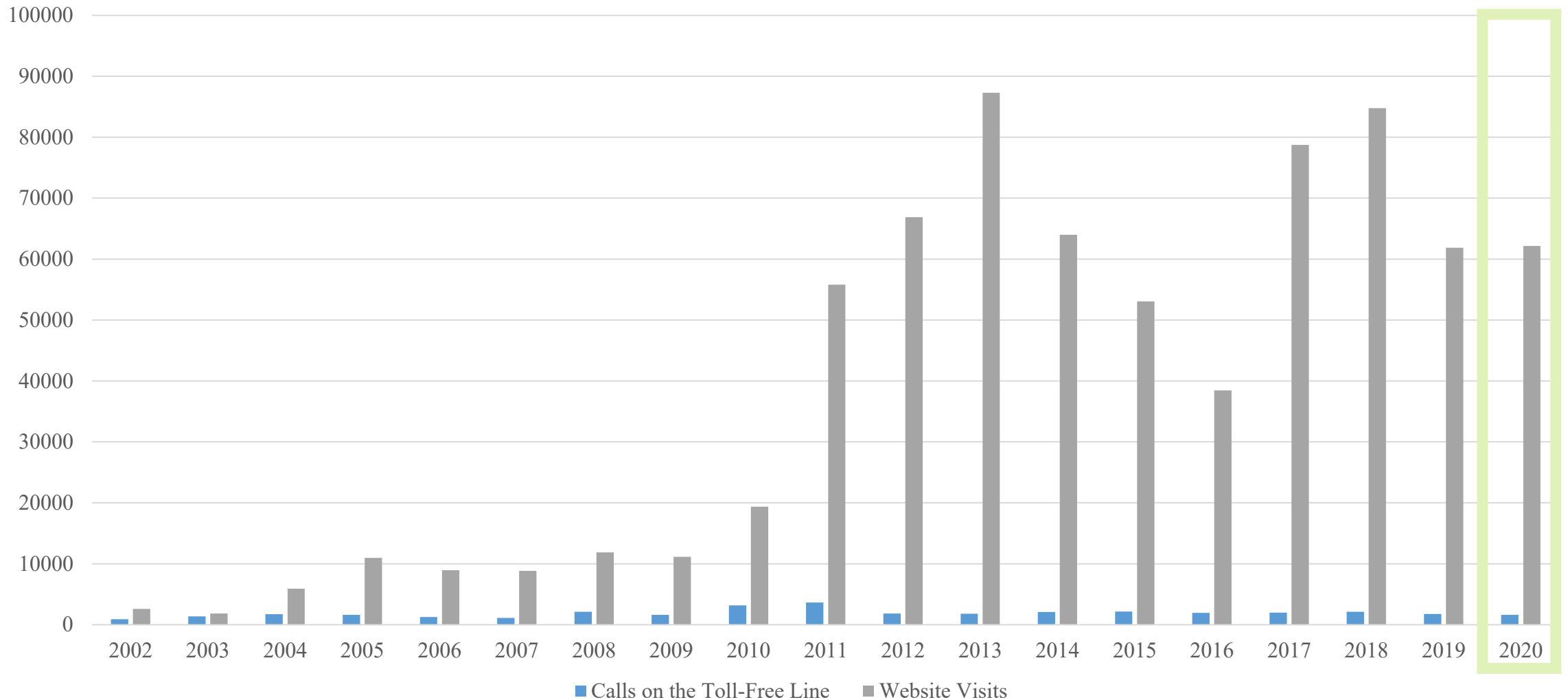
2020 Education and Outreach Opportunities Review	
Community opportunities	7
Professional opportunities	6
College lectures	3

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

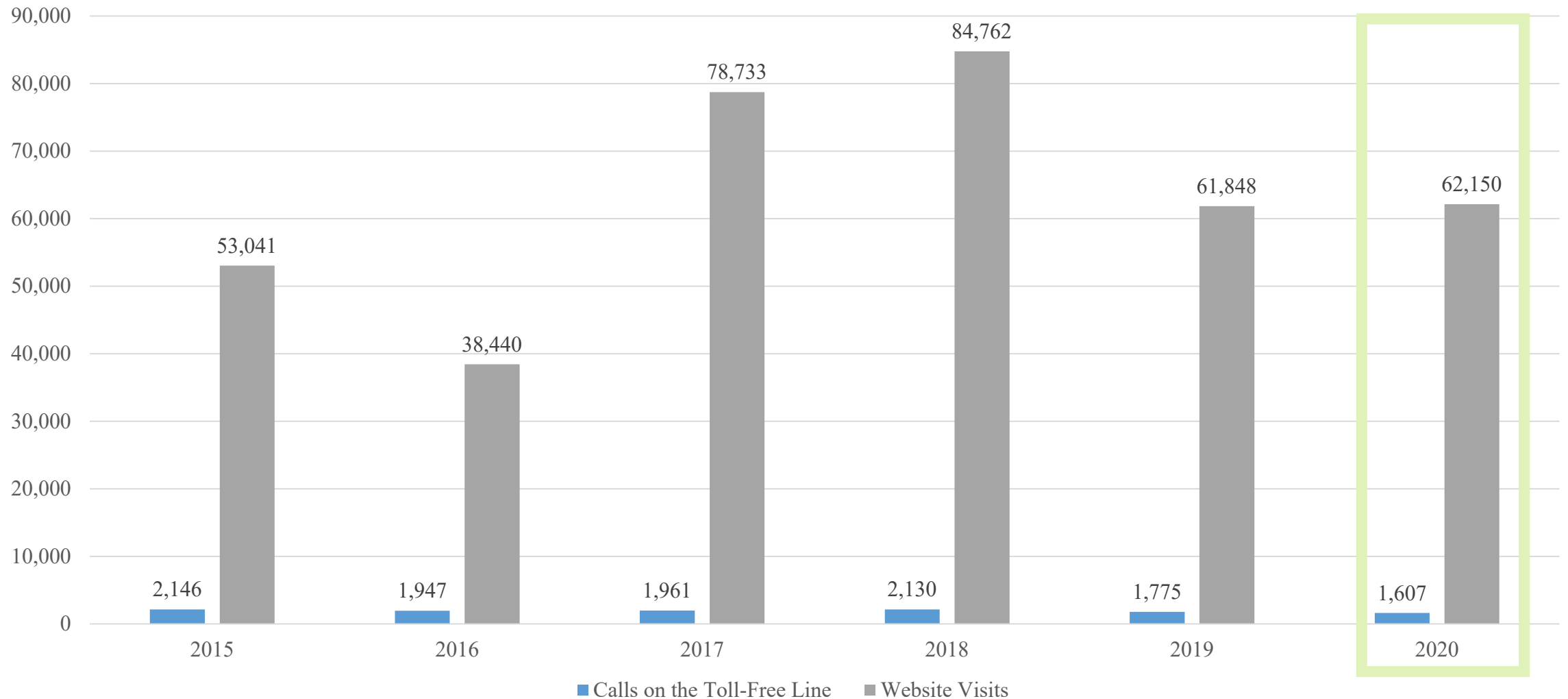
2020 Monthly Review												
	January	February	March	April	May	June	July	August	September	October	November	December
Calls on the toll-free 877-209-8086 line	170	130	300	234	109	103	134	115	81	231	0	0
Website visits	5,298	5,299	6,059	4,822	4,270	4,187	5,522	5,572	5,486	5,742	4,959	4,934

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

Total Communication 2002-2020



6 Year Communication Trend 2015-2020





West Virginia Center for
End-of-Life Care

e-Directive Registry

Annual Report 2020

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WV Center for End-of-Life Care, e-Directive Registry Mission Statement

The West Virginia Center for End-of-Life Care, with support from the WV Health Information Network, established the WV e-Directive 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 e-Directive 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 e-Directive Registry uses an opt-in system, requiring patients' consent to having their forms available on the Registry. The Registry has been nationally recognized.

Terms in this report	Definition
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: <ul style="list-style-type: none"> • 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

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

2020 Registry Form Review and Totals

Forms Received	12,813 (2.27% decrease)
Active Forms	10,281 (18.72% increase)
Archived Forms	2,532 (43.10% decrease)
RR Forms	10,300 (0.49% decrease)
NRR Forms	2,513 (8.92% decrease)

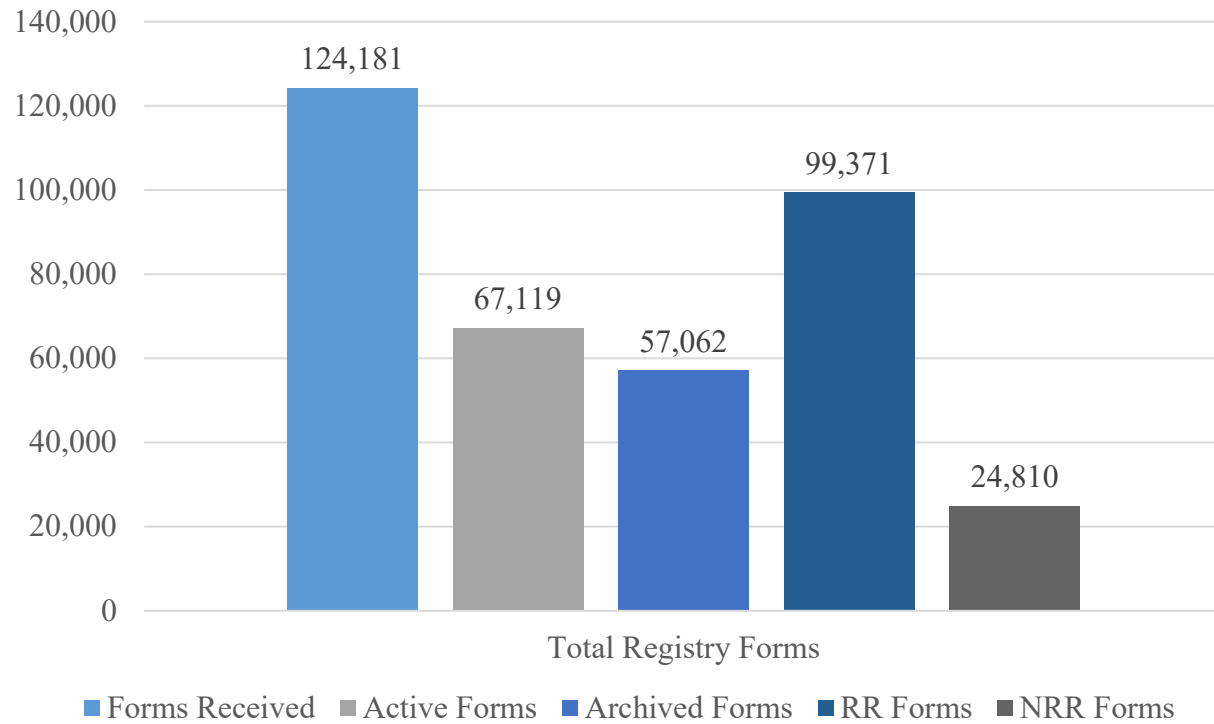
Cumulative Registry Patient Review and Totals (10/1/2010 – 12/31/2020)

All Patients	91,384
Archived Patients	55,748

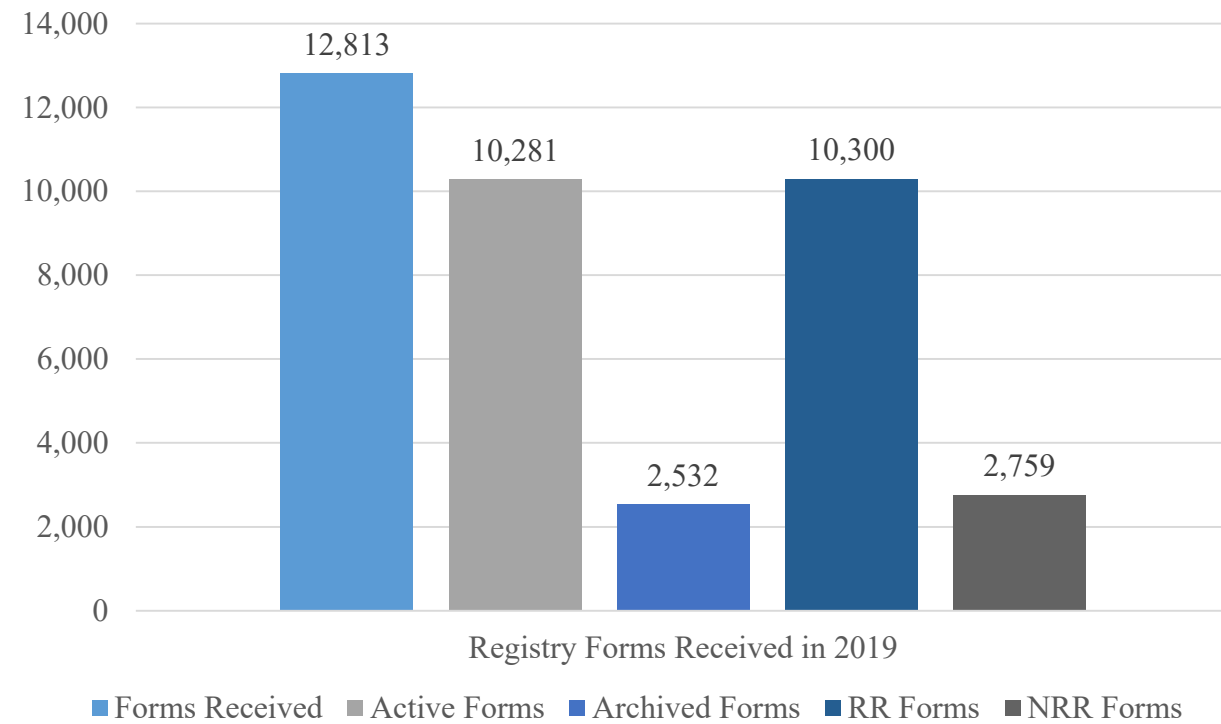
2020 Registry Patient Review and Totals

New Patients	8,522 (18.19% decrease)
Archived Patients	3,261 (6.29% decrease)

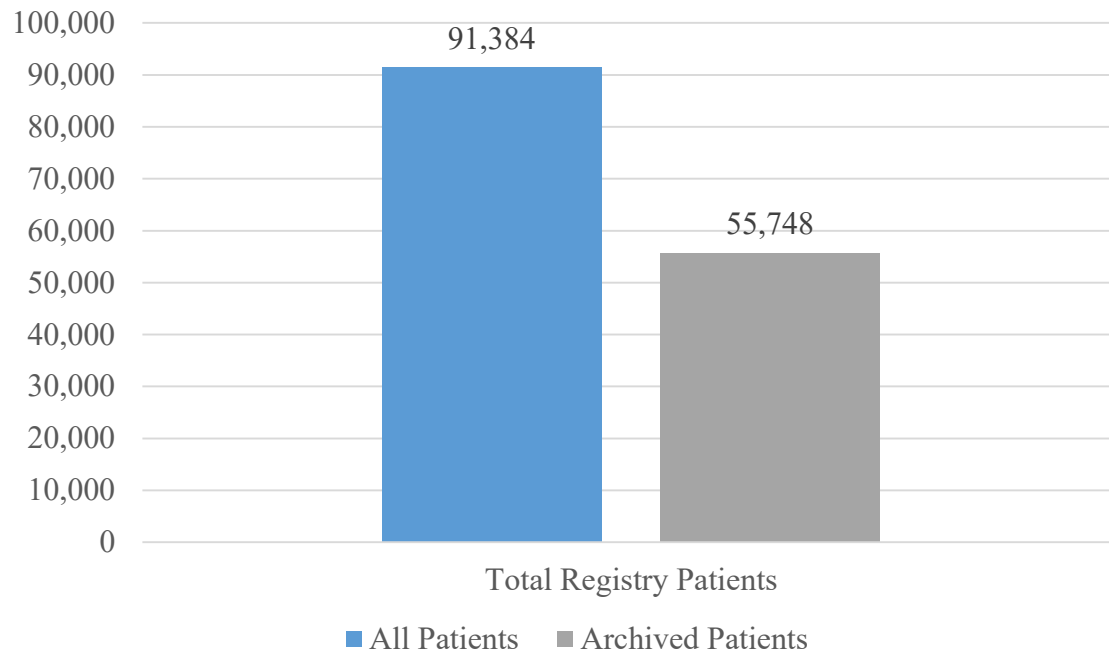
Total Forms Received by Classification 2010-2020



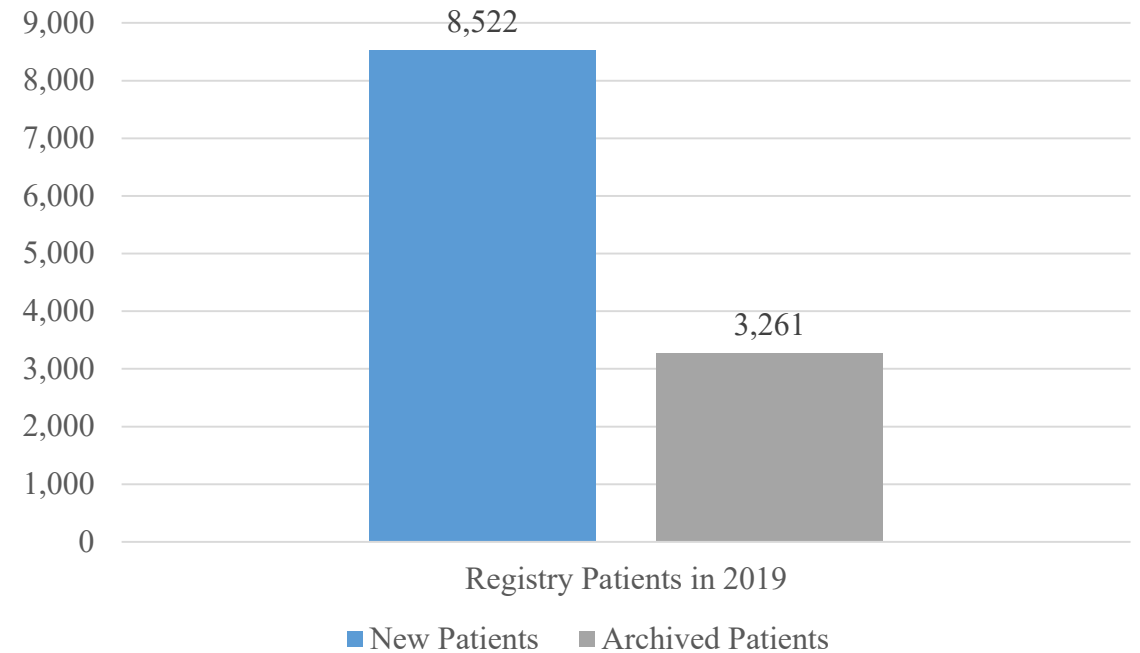
Forms Received by Classification in 2020



Total Registry Patients 2010-2020



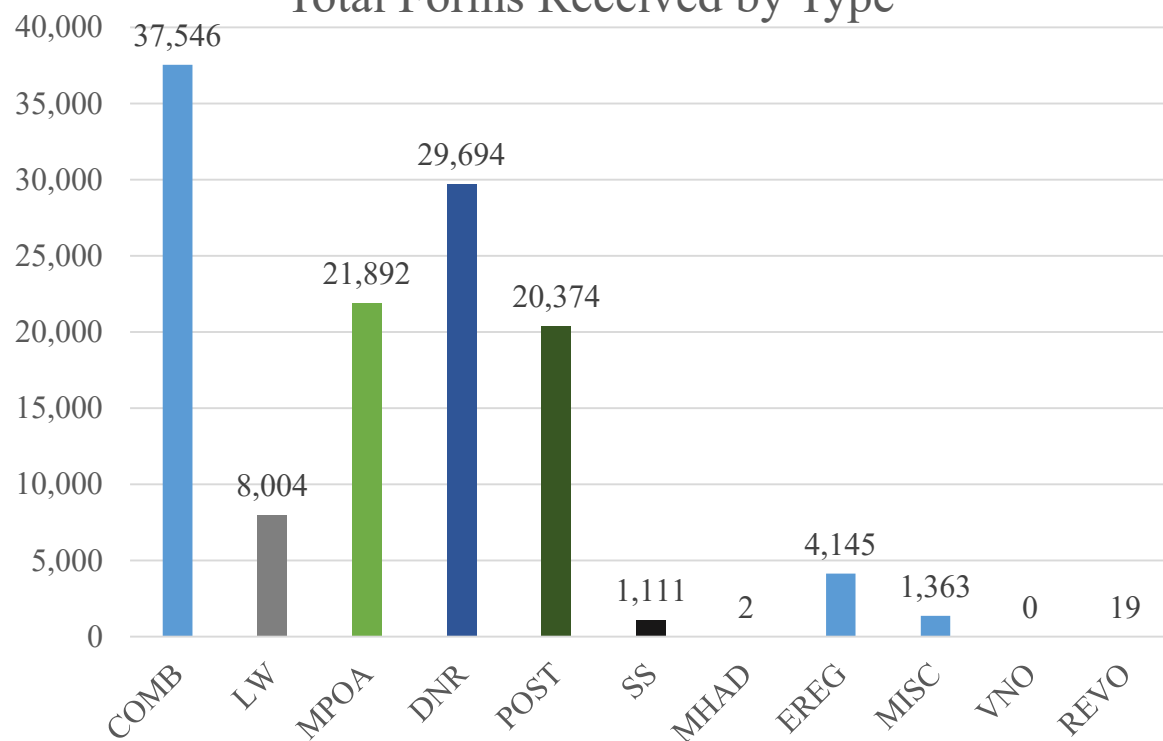
Registry Patients in 2020



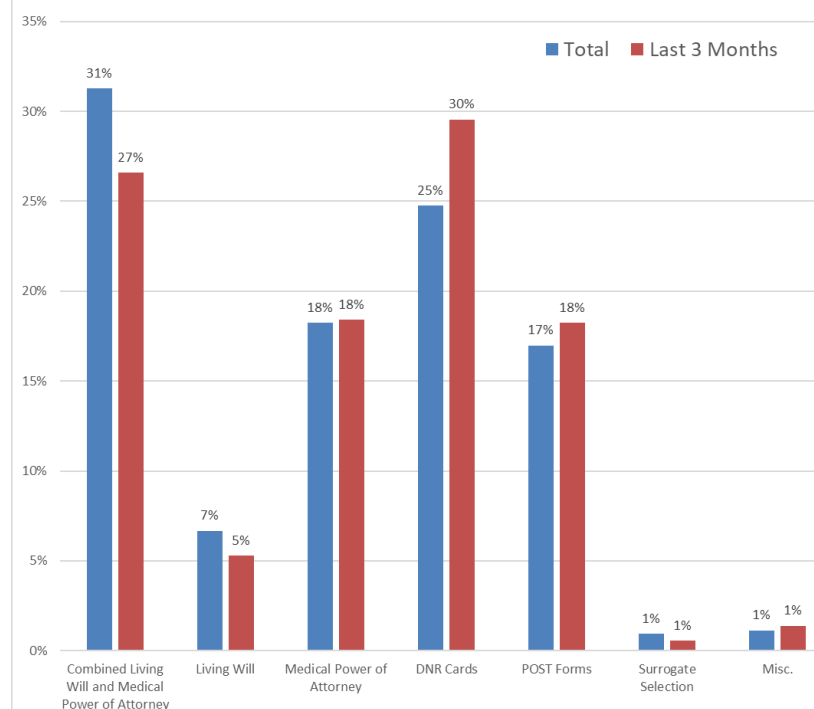
Total Forms Received by Type and Classification 10/1/2010 – 12/31/2020

	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

Total Forms Received by Type



Registry Forms Received by Type



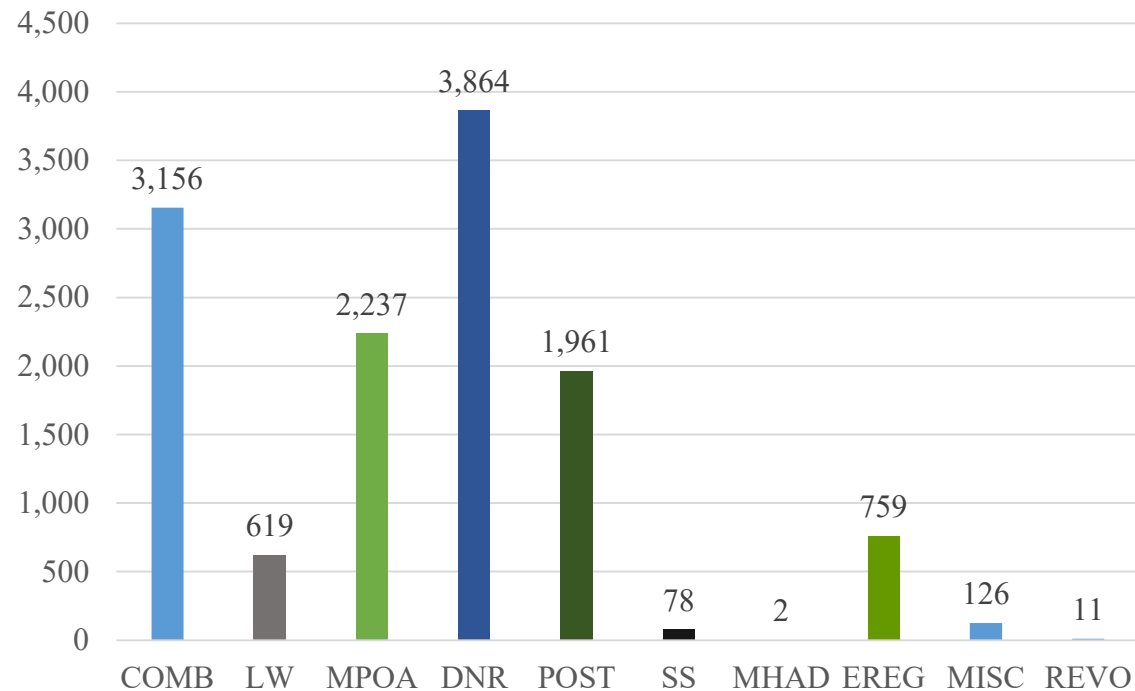
As of December 31, 2020

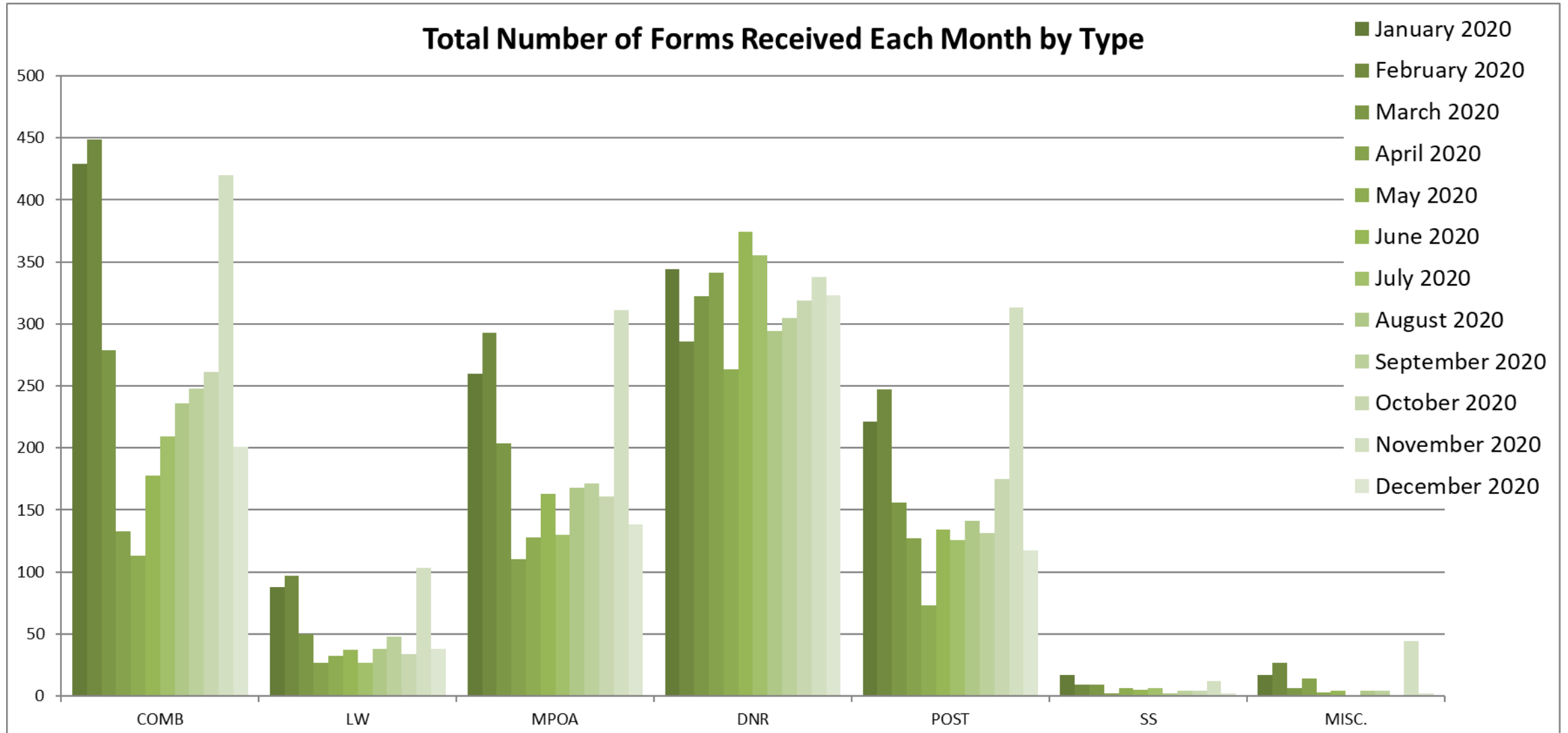
*Figure does not display data for MHAD (2), EREG (4,145), or REVO (19)

Forms Received by Form Type and Classification in 2020

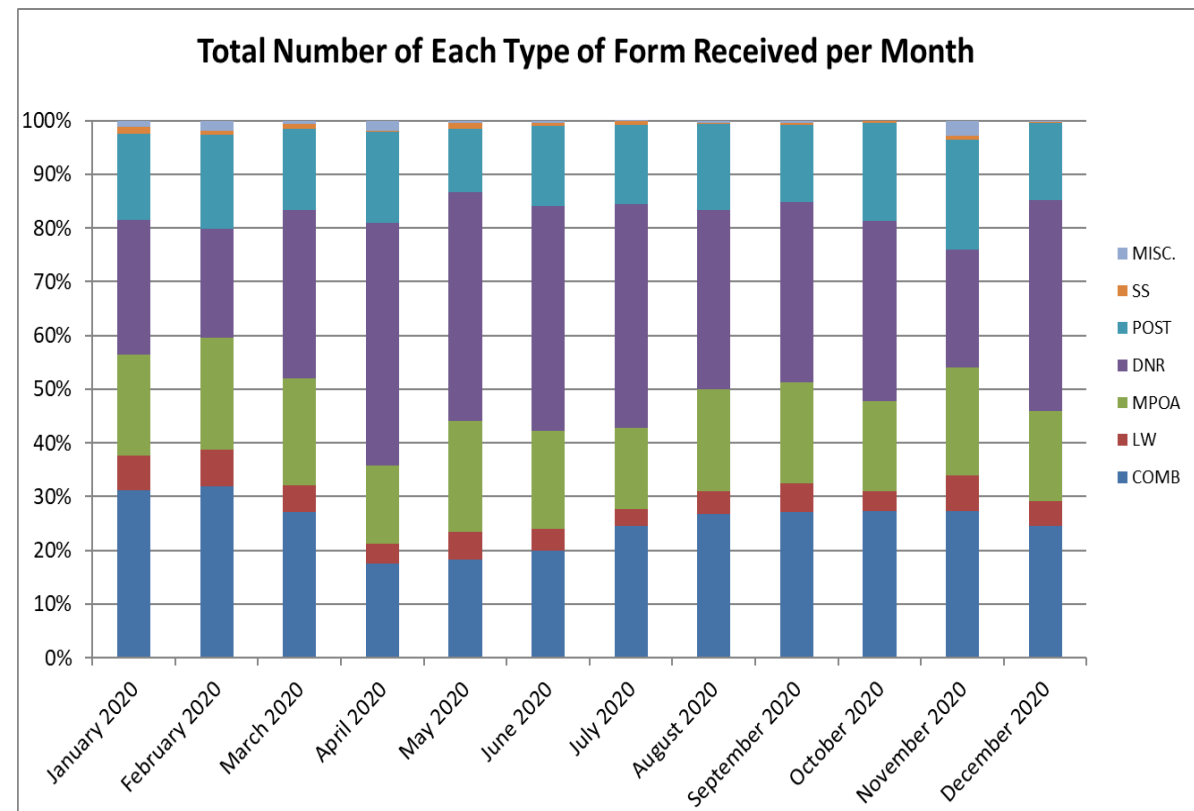
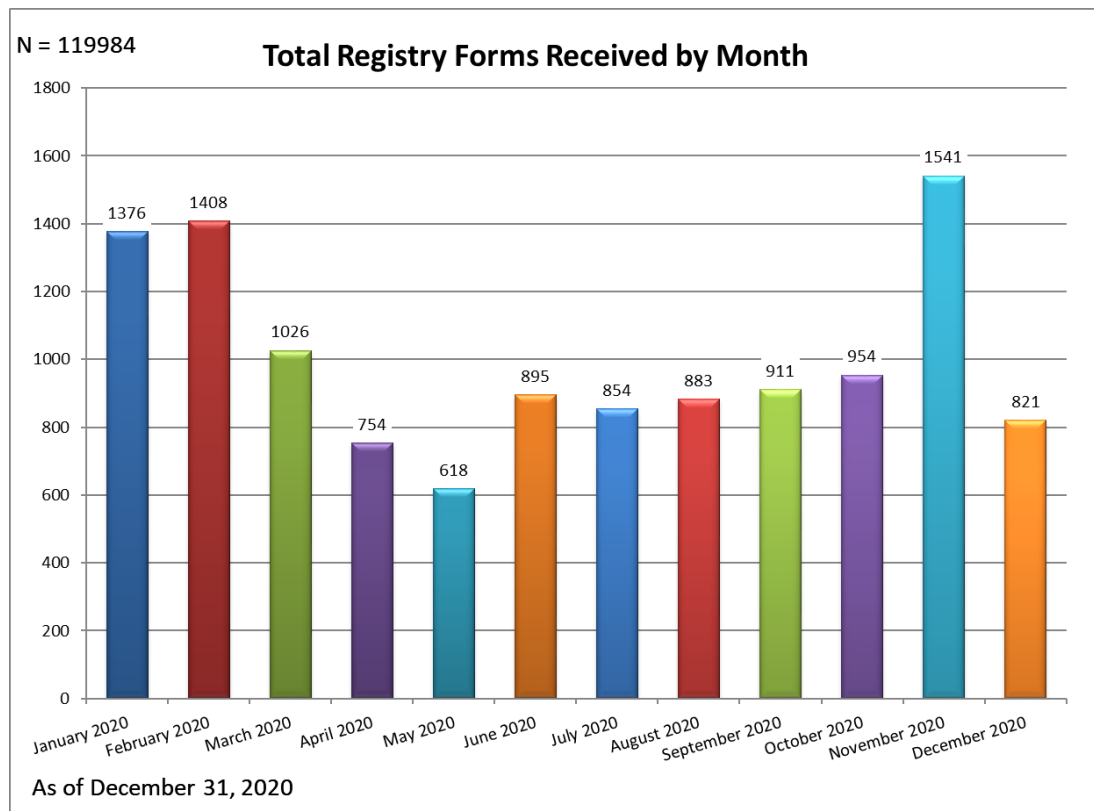
	COMB	LW	MPOA	DNR	POST	SS	MHAD	EREG	MISC	VNO	REVO
Forms Received	3,156	619	2,237	3,864	1,961	78	2	759	126	0	11
RR Forms	2,663	402	1,614	3,334	1,433	40	2	753	53	0	6
NRR Forms	493	217	623	530	528	38	0	6	73	0	5

Forms Received by Type in 2020

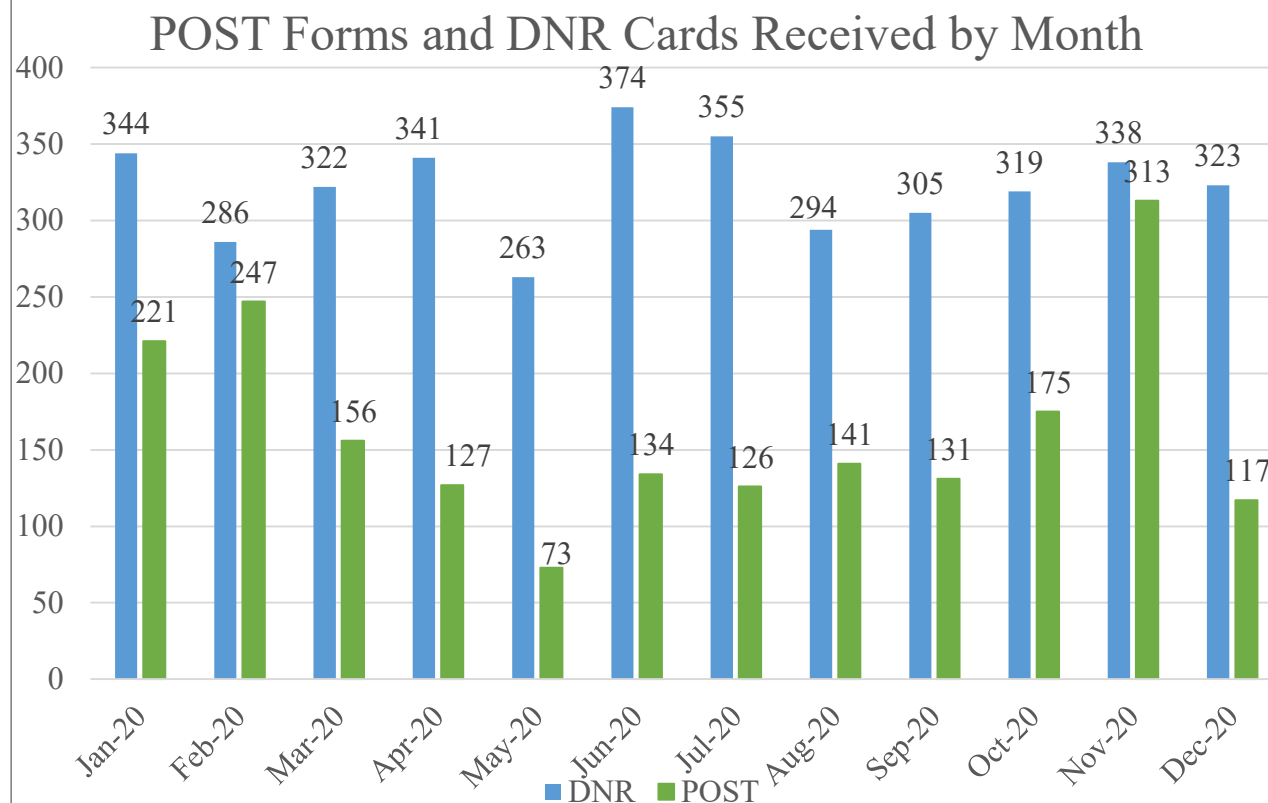
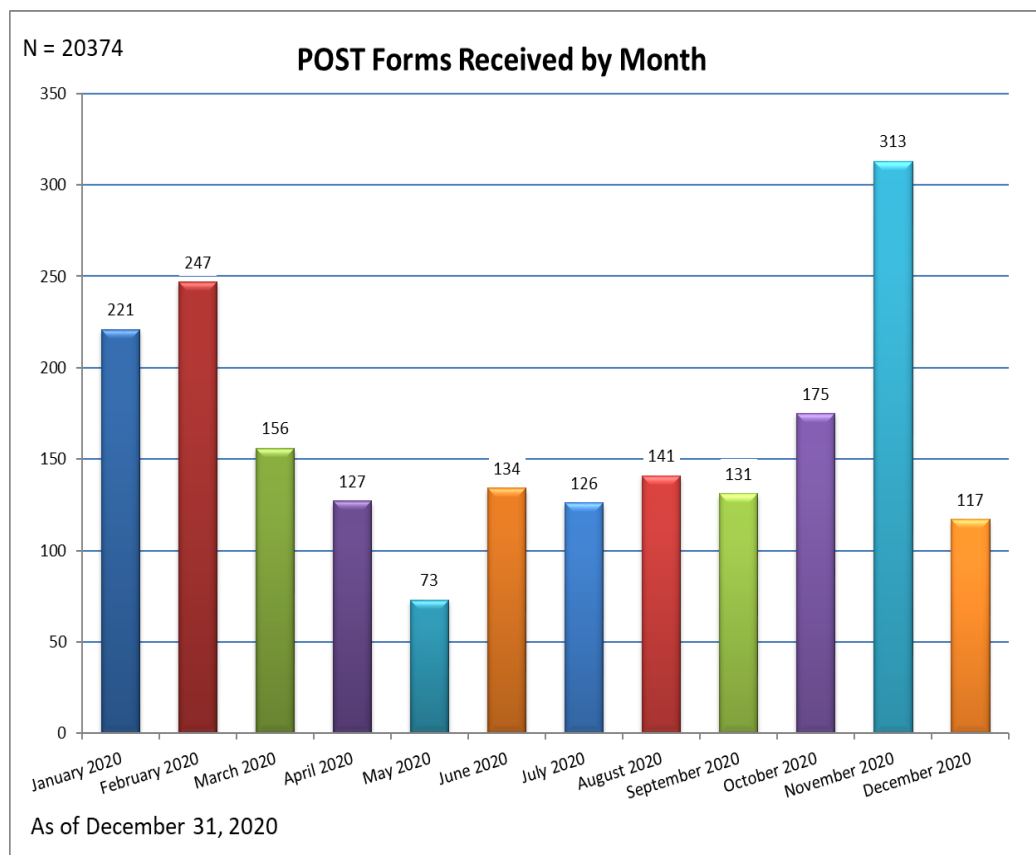




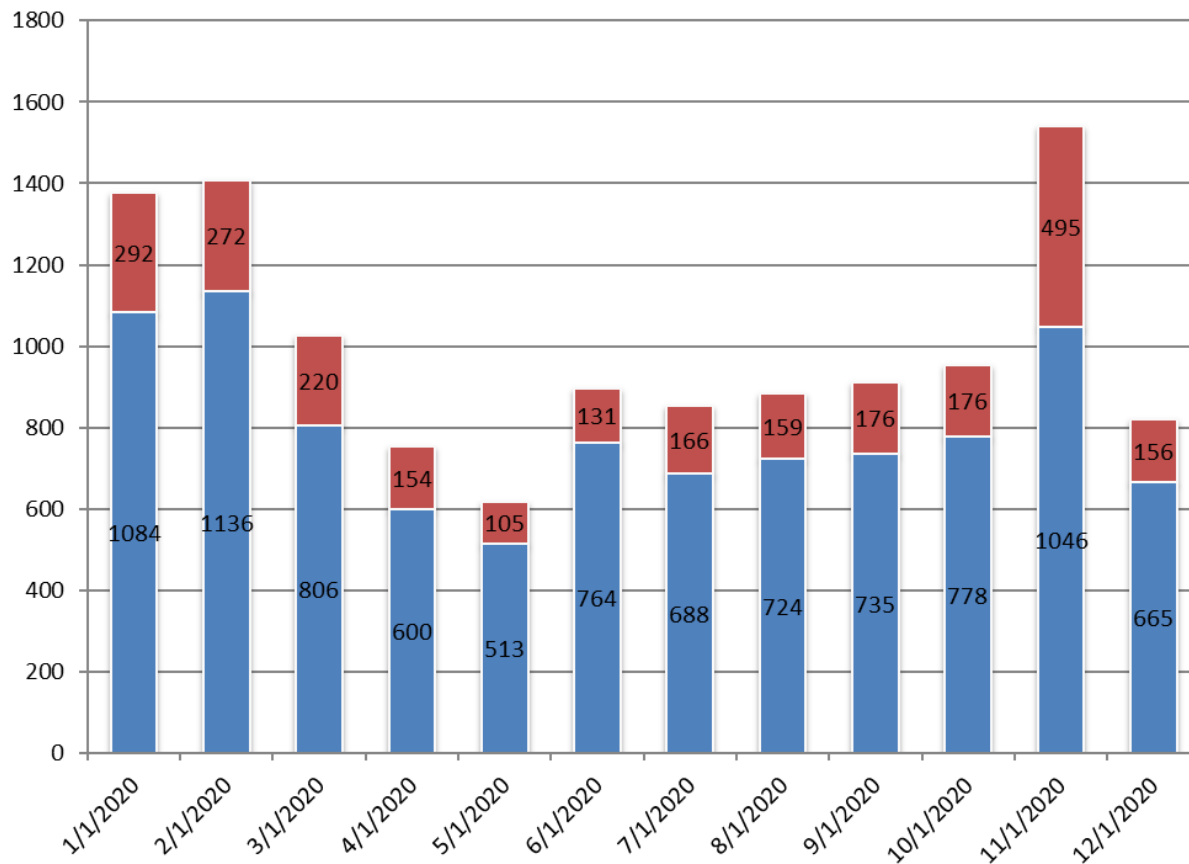
**Figure 13 does not display data for MHAD (2), EREG (759), or REVO (11)*



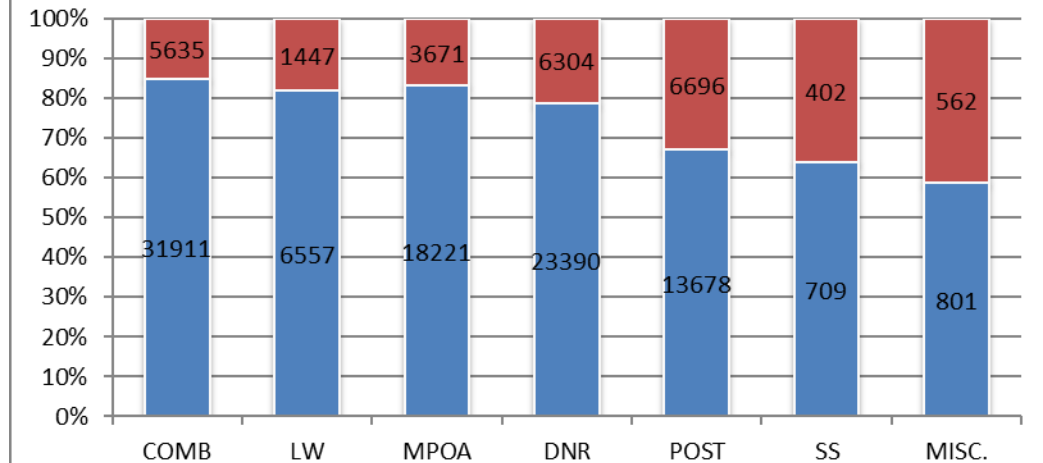
*Figures do not display data for MHAD (2), EREG (759), or REVO (11)

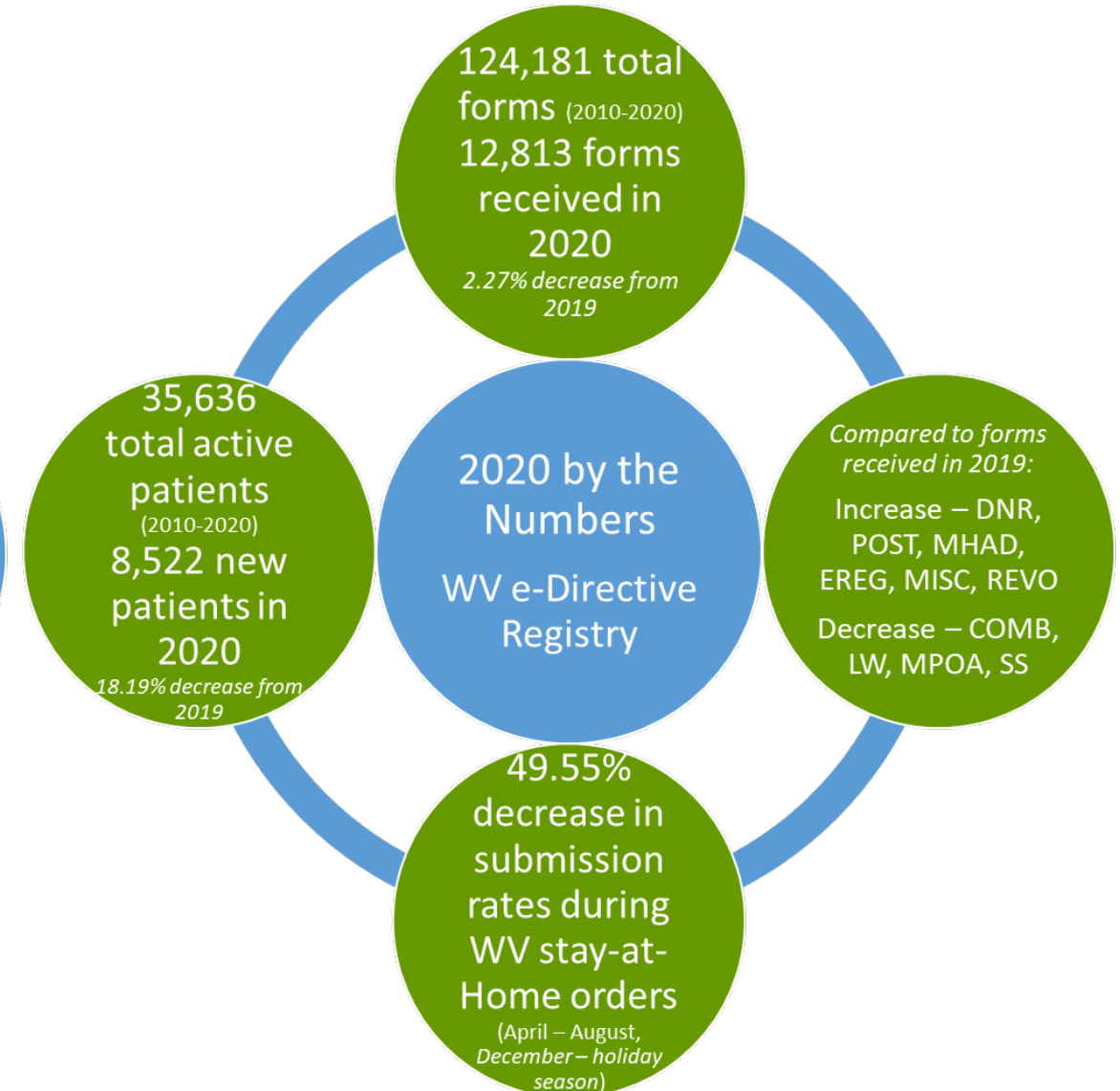
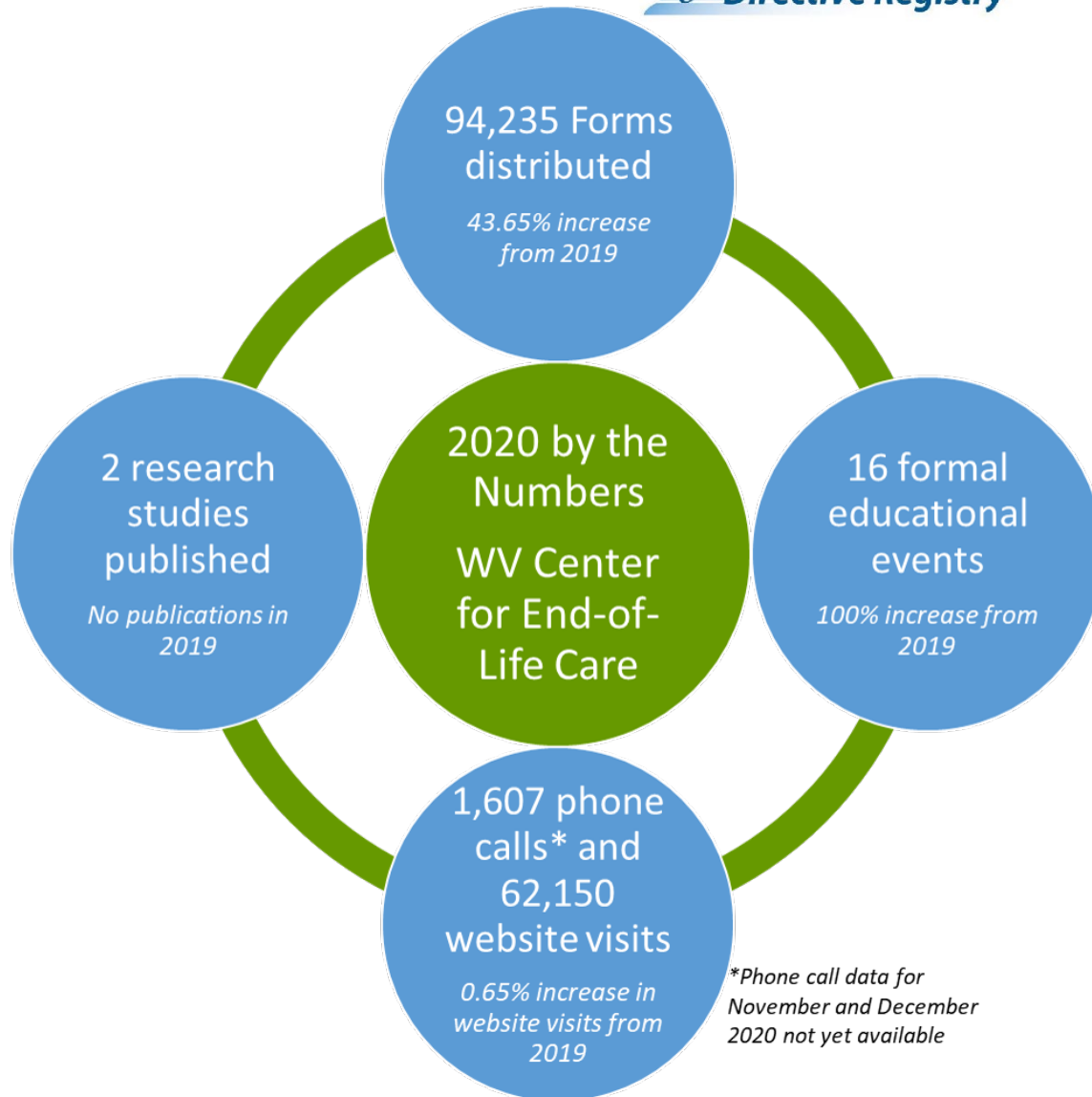


RR vs NRR Received by Month



RR vs NRR Received by Type





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>

2020 Educational and Outreach Opportunities (continued)

Event Date	Event Name <i>Type</i>	Presenter(s)	Number of Attendees
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
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	
12/02/2020	Morgantown Magazine: Insider’s Guide to Senior Living, “Advance Care Planning” <i>Community informational outreach opportunity</i>	Danielle Funk	<i>Magazine available publicly</i>

2020 Personnel	
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 Moss, MD, FACP, FAAHPM

2020 Finances	
\$97,000	<u>Personnel budget</u> – divided amongst 2 full-time employees (salaries, fringes, benefits) and one student worker (through January 2020)
\$25,500	<u>Registry upgrade</u> to a custom application system (payment 1 of 2)
\$19,410	<u>Secure hosting charges</u> of Registry data with PHI protection and liability
\$6,020	<u>Printing charges</u> for medical orders and Registry mass mailings
\$5,345	<u>Postage charges</u>
\$2,075	<u>Secure electronic faxing</u> services with PHI protection
\$1,100	<u>Computer supplies</u>
\$945	<u>Telephone charges</u> for the toll-free line
\$100	<u>Ink charges</u> for printing of resources other than medical orders and Registry mass mailings

Search the WV e-Directive Registry 24/7

Through the WV Health Information Network

The West Virginia Health Information Network's (WVHIN) unified landing page (ULP) shows all the patient's information including any Registry documents. In 2020, over 1,460 accounts were authorized to access the Registry through WVHIN's ULP.

2020 WV e-Directive Registry on WVHIN's ULP Top Health Care Facilities	
Top user	Ruby Memorial Hospital Care Management
<i>Tied for Second</i>	Davis Medical Center
<i>Tied for Second</i>	Thomas Memorial Hospital

Well done to Ruby Memorial Hospital Care Management!

They used the ULP to find Registry forms **7 times more** than the second place facilities!

2020 WV e-Directive Registry on WVHIN's ULP Top Individual Users	
Top user	Katherine Prescott, Ruby Memorial Hospital Care Management
Second highest user	Maggie Phillips, Thomas Memorial Hospital
Third highest user	Elizabeth Grime, Davis Medical Center

Kudos to Katie!

She used the ULP to find Registry forms **4 times more** than the second place user!

Email info@wvhin.org or dcfunk@hsc.wvu.edu to become a member of WVHIN.



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