

# Advance care planning among users of a patient portal during the COVID-19 Pandemic: A retrospective observational study

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#### Abstract

**Background:** Advance care planning is the process of discussing health care treatment preferences based on patients' personal values and often includes the completion of advance directives. In the first months of 2020, the novel coronavirus SARS-CoV-2 began circulating widely in Colorado, USA, leading to widespread COVID-19 diagnosis, hospitalizations, and deaths. In this context, technology-based, non-face-to-face methods to conduct advance care planning via patient portals became increasingly important.

**Objective:** Determine the rates of online advance care planning tool use through a health system-based electronic patient portal, before and in the early months of the COVID-19 pandemic.

Methods: In 2017, we implemented online tools for patients to learn about advance care planning and complete an electronically-signed medical durable power of attorney (MDPOA) to legally appoint a medical decision maker. The tools are available through the patient portal of UCHealth's electronic health record (EHR). UCHealth cares for 1.9 million patients in 12 hospitals and associated clinics in Colorado and parts of Wyoming and Nebraska. The advance care planning tools also provide patient-centered education and include an option to send an electronic message with questions to a UCHealth staff member. Patients accessing the portal can complete and submit a legally valid MDPOA that becomes a part of their medical records. We collected data on patients' date of MDPOA completion, use of advance care planning messaging, age, sex, and geographic location during the early phases of the COVID-19 pandemic (December 29, 2019 to May 30, 2020).

**Results:** Over a five-month period that includes the early COVID-19 pandemic in Colorado, total monthly advance care planning portal tool use increased from 418 users in January to 1037 users in April, and then was slightly lower with 815 users in May. The number of MDPOA forms submitted per week increased 2.4-fold after the Colorado "stay-at-home" order was issued on March 26, 2020 (p<0.0001). Portal advance care planning users were mean age of 47.7 (16.1) years and 67% female. The largest age group of users were 25-35 years of age (22%), compared to age 65 years of age and older (19%). Females were more likely to complete an MDPOA particularly in younger age groups (p<0.001). The primary use of the advance care planning portal tools was the completion of an MDPOA (95.3%), compared to sending an electronic message (4.5%). Over 50% of patients who completed an MDPOA did not have a prior agent in the EHR.

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# **Original Manuscript**

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**Objective:** Determine the rates of online advance care planning tool use through a health system-based electronic patient portal, before and in the early months of the COVID-19 pandemic.

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older (19%). Females were more likely to complete an MDPOA particularly in younger age groups (p<0.001). The primary use of the advance care planning portal tools was the completion of an MDPOA (95.3%), compared to sending an electronic message (4.5%). Over 50% of patients who

completed an MDPOA did not have a prior agent in the EHR.

Conclusions: Use of an online patient portal to complete an MDPOA increased substantially during the first months of the COVID-19 pandemic in Colorado. There was an increase in advance care planning that corresponded with state government "shelter in place" orders, as well as public health reports of increased COVID-19 cases and deaths. Patient portals are an important tool for providing advance care planning resources and documenting medical decision makers during the pandemic to ensure medical treatment aligns with patient goals and values.

**Keywords:** Advance Care Planning; Electronic Health Records; Pandemic COVID-19; Advance Directives; Patient Portal

#### Introduction

On March 11, 2020, the World Health Organization characterized COVID-19 as a pandemic. At that time, there were approximately 118,000 cases in 114 countries, and 4,291 people had died worldwide due to COVID-19. As of June 2020, fatality rates for COVID-19 have been estimated to be between 0.6 to 5% and are highest among older adults and people with chronic conditions.[1, 2] In the United States, the Centers for Disease Control and Prevention reports 14% of COVID-19 patients are hospitalized and 2% are admitted into an intensive care unit (ICU).[2] In these cases, invasive procedures such as mechanical ventilation and extracorporeal membrane oxygenation may be used to treat seriously ill COVID-19 patients. As such, there is a need to discuss goals of care and desired treatments with patients, ideally before they become critically ill.

Advance care planning is the process of discussing medical treatment preferences based on personal values and often includes the completion of advance directives.[3, 4] In the United States, advance directives are state-specific documents that include medical durable powers of attorney (MDPOA) and living wills.[5] Advance care planning is associated with increased advance directive documentation, completion of medical orders for life-sustaining treatment preferences, and positive health outcomes including reduced end-of-life hospitalizations, enhanced patient-provider communication, prevention of unwanted treatment, and improved family experience.[6, 7]

COVID-19 has stimulated advance care planning in emergency departments and ICUs, indicating a need to provide advance care planning interventions and resources prior to admission.[8] With increased social distancing and patient concerns about in-person clinic visits,[8-10] telehealth use has rapidly increased. Centers for Medicare and Medicaid Services reimbursement of telehealth, or the use of electronic information or telecommunication technologies to promote health and health services,[11] has rapidly expanded to cover non-emergent clinical visits, screening for COVID-19, and advance care planning counseling.[12] Telehealth has the potential to provide health care services and applicable advance care planning tools during the pandemic and beyond.[13, 14]

Telehealth-based advance care planning programs are feasible to deliver and effective in improving advance care planning knowledge, communication, and advance directive documentation.[15]

Patient portals allow patients secure access to personal health information contained in their electronic health record.[16] Beyond ability to view health information, patient portals also support patient initiated entry of health information and electronic interactions between patients and providers, promoting engagement in care, including advance care planning.[17-19] Portals thus offer a particularly accessible platform for patients and care partners to learn about COVID-19 treatment options and communicate goals of care with their providers. Over the last 5 years, our research team has partnered with health care system information technology experts, patients, caregivers, and providers to develop, test and implement patient portal advance care planning strategies.[20-24] Specifically, the UCHealth patient portal offers patients ability to learn more about advance care planning through online resources and ability to create an electronically signed MDPOA form to choose a medical decision maker. The objective of this study is to examine advance care planning patient portal usage during the early stages of the COVID-19 pandemic.

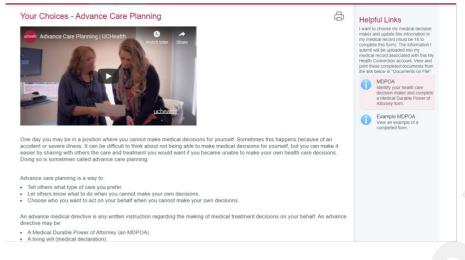
#### Methods

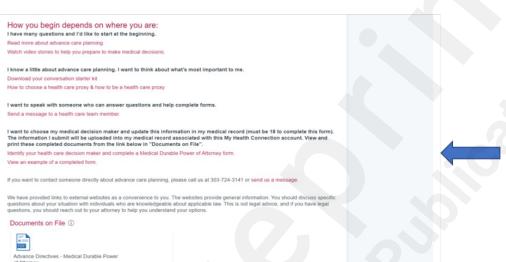
This retrospective observational study examined advance care planning by patients using online advance care planning tools available through the UCHealth patient portal that include the ability to complete legally valid MDPOA forms. UCHealth is a regional healthcare system serving Colorado (including metropolitan Denver, Colorado Springs, Northern Colorado), southern Wyoming, and western Nebraska. In 2019, 1.9 million patients received care in 12 UCHealth hospitals and 800 outpatient clinics. As of May 2020, approximately 735,000 patients have an account for My Health Connection, which is the UCHealth patient portal integrated within the Epic electronic health record (Epic Systems, version 2017, Verona, WI). The Colorado Multiple Institutional Review Board approved this project as evaluation of a clinical initiative.

Patient Portal-based Advance Care Planning Tools

We previously developed and tested tools to conduct advance care planning using the My Health Connection patient portal. [22, 23] Briefly, since July 2017, the advance care planning portal tools provide patients with access to evidence-based resources, ability to send an online message with questions about advance care planning, and ability to complete a legally valid state-specific electronic MDPOA form to choose a medical decision maker. Colorado law allows an electronic MDPOA with a valid patient signature (including electronic) and does not require witnesses or notary signatures. To complete the MDPOA form (Figure 1), a patient-initiated questionnaire provides information about appointing a medical decision maker, shows the exact language of the legal MDPOA form, automates the name of any previously charted medical decision maker from the EHR ('orally appointed' or pre-existing MDPOA), and then allows the patient to name a decision maker and add up to two alternative decision makers. The process creates a printable MDPOA form with an electronic signature and date/time stamp. The decision maker information is displayed in a specific area of the EHR that is accessed by clinical teams. The advance care planning support team is notified of submitted electronic MDPOA forms and briefly reviews the patient's problem list and relevant clinical documentation for possible decision making incapacity, then sends a message to the patient to confirm receipt of the MDPOA form. For out-of-state patients, the message notes that the MDPOA is valid for medical care received in Colorado. Patients can also use the portal message feature to contact the health system's centralized advance care planning support team for questions and follow-up. As additional background, in Colorado, an orally appointed decision maker is a surrogate decision maker verbally chosen by an individual, but that surrogate decision maker does not have as much legal authority as an MDPOA.

Figure 1. My Health Connection Advance Care Planning Tools.





#### Data Collection

Data were collected from December 29, 2019, to May 30, 2020, an approximately five-month period that includes two months prior to community spread of SARS-CoV-2 infections in Colorado. The specific dates were determined to allow 7-day weekly periods to be compared. The first COVID-19 diagnosis in Colorado was announced March 5, 2020. Thus, January and February were effectively "pre-COVID-19" in Colorado. Colorado implemented a state-wide stay-at-home order on March 26, 2020. We collected data through chart review for UCHealth My Health Connection patients who interacted with the patient portal advance care planning tools, specifically by, a) completing an electronic MDPOA form, or b) sending an electronic message to the advance care planning support team. Demographic information included age, sex, and geographic location (i.e., metro Denver, northern Colorado, southern Colorado, out-of-state address). To explore how patients

who submitted an electronic MDPOA were choosing to select a health care agent(s), we categorized patients into the following five groups: a) First time designation of an MDPOA, no prior agent (orally appointed or MDPOA) in the EHR, b) Prior orally appointed agent in the EHR and electronic MDPOA does not change agent, c) Prior MDPOA on file and electronic MDPOA does not change agent, d) Prior MDPOA on file and electronic MDPOA names a new agent, and e) Prior orally appointed agent in EHR and electronic MDPOA names a new agent. "Prior MDPOA" could include any MDPOA form in the patient's EHR, either a paper document that was scanned into the patient's record or a previously submitted electronic MDPOA. We also identified invalid MDPOA submissions, based on advance care planning support team review and discussion with patient and/or clinical team, as previously described[23]. Invalid MDPOA submissions were often the submission of an MDPOA form by someone other than the patient when the patient did not have decision making capacity to choose a health care agent.

#### Data Analysis

We used descriptive analyses to describe patient portal user characteristics expressed as frequencies with percentages. Age categories were chosen to align with state-based surveys of community-based advance care planning rates.[25] We used Chi-squared tests to test gender differences across the age group distribution. Time series analysis were conducted on all data. To explore the change in use of patient portal advance care planning tools, we used nine weeks of data before and after March 26, 2020 (date of Colorado's stay-at-home order). All tests for statistical significance were two-tailed, and a p-value of less than 0.05 was considered statistically significant. All statistical analyses were done using SAS version 9.4.

#### Results

Over a five-month timeframe that includes the early COVID-19 pandemic in Colorado, the number of user clicks on the UCHealth advance care planning patient portal page increased from 3,511 in January to 6,819 clicks in April, and 10,077 clicks in May. Total monthly advance care

planning portal tool use increased from 418 users in January to 1037 users in April, and then was slightly lower with 815 users in May (Figure 2). Week-to-week MDPOA completions varied within each month but with a positive trend line and greater use in April and May (Figure 3). In an interrupted time-series analysis, the number of MDPOA forms submitted per week increased by 92 MDPOA forms per week after the Colorado stay-at-home order was issued on March 26, 2020 (p<0.0001). The weekly rate was 2.4-fold higher in the nine weeks after March 26 compared to the nine weeks prior to March 26. Figure 3 shows submissions of MDPOA forms though the UCHealth patient portal in the cultural context of health orders from the State of Colorado. On March 26, 2020, the Colorado Governor issued a state-wide stay-at-home policy.[26] On April 5, Colorado approved and publicized Crisis Standards of Care documents as guidelines for how the medical community should allocate scarce resources such as ventilators and intensive care unit beds in the extreme case when patient needs exceed the resources available.[27] The Colorado Department of Public Health and Environment also updated the state-wide number of cases and deaths among individuals with COVID-19 throughout this time period.[28]

Figure 2: Monthly use of advance care planning portal in the COVID-19 pandemic, by type of portal use.

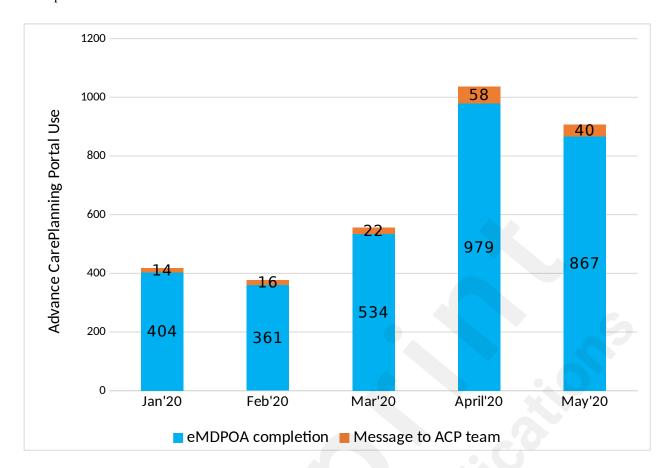
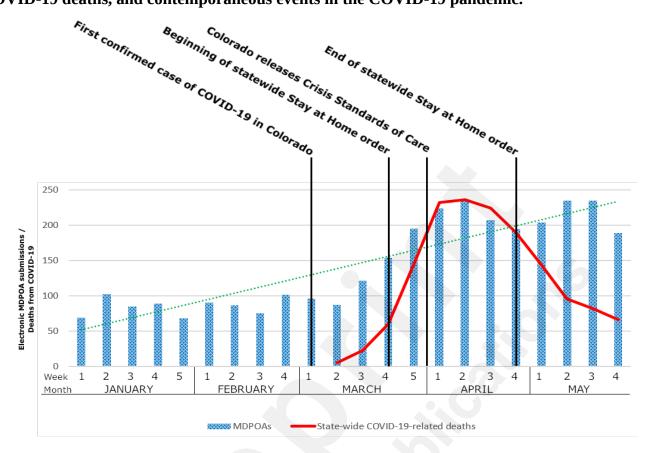


Figure 3: Weekly use of advance care planning portal for eMDPOA completion, statewide COVID-19 deaths, and contemporaneous events in the COVID-19 pandemic.



From December 29, 2019, to May 30, 2020, 3,292 patients used the advance care planning portal tools. Patients were mostly female (67%) with a mean age of 47.7 years (16.1). Patients who used the advance care planning portal tools were relatively evenly distributed between ages 25 years and 65+ years (Table 1). The largest group of users was ages 25-34 years. The age distribution in our total population differed significantly between females and males (p<0.0001), where the proportion of women who used the advance care planning portal tools was greater than men for all age groups, and significantly larger in the younger age groups (Table 2). Regionally, all three health care regions of UCHealth were represented with 43% from the metro Denver region.

Table 1. Patient portal user characteristics (N=3,292)

Age	N	%
18-24 years	148	4%
25-34 years	721	22%
35-44 years	684	21%
45-54 years	578	18%

55-64 years	543	16%
65+ years	618	19%
Sex		
Female	220	67%
	6	
Male	108	32%
	2	
Non-Binary	4	1%
Region		
	141	
Metro	2	43%
	102	
North	1	31%
South	719	22%
Out of state	140	4%
Type of Interaction		
eMDPOA Completion	313	95%
	8	
Message to ACP support team	148	4.5%
Invalid MDPOA submission	6	0.2%
eMDPOA Subgroups*		
No prior agent (oral or MDPOA) and eMDPOA selects a new agent	166 5	51%
Prior MDPOA form and eMDPOA does not change choice of agent	644	20%
Prior MDPOA from and eMDPOA selects a new choice of agent	78	2.0%
Prior orally appointed agent and eMDPOA does not change choice of agent	686	21%
Prior orally appointed agent and eMDPOA selects a new choice of agent	65	1.3%

<sup>\*</sup>Totals to 95.3% (Proportion of total eMDPOAs); eMDPOA – Electronic Medical Durable Power of Attorney; ACP – advance care planning; Users from 12/29/19-5/30/20.

The primary use of the advance care planning portal tools was the completion of a MDPOA (Table 1). Over 50% of patients who completed an MDPOA did not have a prior agent in the EHR; thus, for 1665 patients, their completion of the MDPOA resulted in naming a medical decision maker and ensuring that this information would be available to their health care providers. An additional 21% of patients officially appointed a previously orally appointed person to be their legal medical power of attorney by submitting the MDPOA form. The third largest group of patient users (20%) were patients who already had an MDPOA on file, and the new MDPOA did not change their primary medical power of attorney, though in some cases they changed an alternate decision maker or added specific instructions as part of the form. Six patients in the four-month period submitted an

invalid MDPOA by selecting themselves as the decision maker or lacked decision-making capacity as determined through quality assurance review and discussion with the primary care provider or emergency contact.

Less than 5% of patient portal users who used the advance care planning tools sent an electronic message to a centralized advance care planning support team. The majority of these messages were questions related to how users could submit existing paper advance directives so that the advance directives would be available in the EHR (a feature that is planned, but not currently available).

Table 2. Use of the Advance Care Planning Patient Portal Tools by Age and Gender.

Age	Female	Male	
generation	N (%)	N (%)	p-value
18-24 years	124 (84%)	24 (16%)	<.0001
25-34 years	569 (79%)	151 (21%)	
35-44 years	465 (68%)	217 (32%)	
45-54 years	381 (66%)	197 (34%)	
55-64 years	334 (62%)	208 (38%)	
65+ years	333 (54%)	285 (46%)	

#### Discussion

To our knowledge, this is the first study to identify a significant increase in patient-initiated completion of an electronic MDPOA through the patient portal during the COVID-19 pandemic. In the context of COVID-19, conducting advance care planning is increasingly important to ensure patients have identified medical decision makers they trust and that they receive treatment that aligns with their values and preferences. Patient portals are a particularly useful tool for advance care planning during a pandemic because they are accessible 24-hours a day, do not require face-to-face contact, and are directly linked to health care providers and the EHR.

A significant increase in advance care planning portal tool use was seen in April, 2020, aligned with increased awareness of the surge in COVID-19 cases, hospitalizations, and deaths in Colorado, the State of Colorado's stay-at-home order (March 26, 2020 – April 26, 2020), and the

widely-publicized authorization of the state's Crisis Standards of Care on April 5. The trend in increased MDPOA completion began in March, closely aligned with the announcement of the first case in Colorado (March 5, 2020). Although advance care planning is currently taking place in emergency departments and ICUs,[8] these portal users did not submit the MDPOA during an inpatient encounter (data not shown). These users are likely accessing their patient portal account and documenting their preferences at home, away from the clinic, and prior to possible emergency care. The existing MDPOA can streamline and enhance quality of communication during a time of potential health system strain.

Approximately half of the MDPOA forms submitted during this timeframe were new submissions, suggesting that in setting of COVID-19, people are interested in advance care planning and documenting their health decision maker. COVID-19 has prompted patients to have heightened awareness of the potential of becoming seriously ill. These findings show that patients are willing to act on this knowledge without marked investment of health system resources. While health care providers are calling for improved advance care planning during the pandemic, there is little known about patient needs and preferences regarding COVID-19-specific advance care planning processes. The technology of the portal may be an important facilitator. An electronic MDPOA can overcome barriers related to lack of documentation access, lack of ability to share completed forms with the health care system, and perceived time, financial, or legal barriers. These users may welcome the ability to complete the MDPOA through the patient portal instead of with an attorney or health care practitioner because of the need for dedicated appointments, which were likely difficult to access due to stay-at-home orders and clinic preference for telehealth appointments.

During a recent qualitative advance care planning patient portal study, older patients and their caregivers indicated a need for easy access to their current/active MDPOA via the portal.[29] Access to the MDPOA allows for the ongoing review and updating of patient preferences, which is an important aspect of advance care planning as an ongoing process.[4, 30, 31] While less frequent,

patients used the advance care planning message tool, and over half of the messages during the study period were in the month of April. This corresponds with the MDPOA completion spike in April and indicates people who are interested in using the portal for advance care planning want to use the portal to share existing advance directives or may need technical assistance to use the portal. Patients have previously reported the need for technical assistance in using advance care planning portal tools.[29]

Patients across the age spectrum used the advance care planning portal tools. Surprisingly, the largest age group of users was 25 to 34 years of age, demonstrating that they are interested in engaging in advance care planning by choosing a medical decision maker. Advance care planning typically increases with age.[32, 33] In Colorado, only 17% of adults age 25-34 years have an advance directive compared to 66% of adults over the age of 65.[25] Although it is recommended to engage young adults in advance care planning, the majority of efforts target older adults or focus on young adults with life-limiting illness. Lack of advance care planning awareness and healthy young adults' perception that advance care planning is unnecessary are two major barriers. However, young adults who have previous experiences with a seriously ill loved one have demonstrated increased advance care planning awareness and preference to complete an advance directive.[30, 31] Contextually, at the end of May, 2020, approximately 33% of Coloradans diagnosed with COVID-19 were between the ages of 20-39 (approximately 8,728 individuals, as reported on June 6, 2020), and 6.6% of these cases resulted in hospitalization.[28] Since COVID-19 does not only affect older adults, young people may see the value in advance care planning. The patient portal mechanism for advance care planning documentation aligned with health communication and health information access values patients in the younger age demographic, allowing patient portals to be a sustaining strategy for promoting advance care planning in this population.[34]

In addition to advance care planning, age is also associated with patient portal adoption and use.[35, 36] Healthy young adults and older adults, particularly those over the age of 75, are less

likely to register for a patient portal account and regularly use portal features. While younger adults typically associate non-use to their health status, older adults attribute portal non-use to lack of technology access or technical barriers.[37] Our studies indicate that regardless of age and these barriers, patients chose to use their portal for advance care planning. However, efforts should be made to increase advance care planning awareness among younger adults and address technical concerns among older adults.

Among this cohort, women were more likely to complete an MDPOA across all age groups, but this difference was more pronounced in younger age groups. Gender differences have been found in both patient portal use and advance care planning, with females being more likely to engage with a portal [36] and with advance care planning. [25, 32, 33] Even among young adults, a national survey found that males reported less familiarity with the concepts of advance care planning, advance directives, and health care proxy. [30] In Colorado, approximately 48% of COVID-19 cases are among males, but males represent 56% of COVID-19 deaths. [28]

There are limitations to our study. Our data lacked race, ethnicity, education status, and specific geographic information (i.e., zip code) to determine rurality, which are all known to impact access to health care, health technology use, and advance care planning engagement.[32] We also did not capture the health status, medical diagnoses, prior engagement with advance care planning, or preferences related to consumer health technology overall, which also could be associated with patient portal use. While our study identified a significant increase in engagement with the portal over time, due to the retrospective cohort design of our study, we are unable to conclude that this increase is solely caused by the COVID-19 pandemic rather than other secular trends. Also, it is difficult to predict if the observed growth will be sustained throughout the pandemic period or if there was an immediate effect during the Stay at Home Order. As seen in Figure 2, there was a slight decrease in May, and therefore ongoing investigation of the rate of engagement via the portal is warranted as attention to advance care planning is beneficial as COVID-19 continues to spread

across the United States. However, the use of eMDPOA is not feasible in all states due to state-level requirements therefore limiting generalizability across states where state laws may preclude use of the portal for completion of a legal MDPOA. Future research is needed to assess these potential covariates and capture user experiences regarding advance care planning portal use. Research should explore possible associations between patient MDPOA completion and the care provided in the treatment of COVID-19.

In conclusion, the use of a patient portal to complete a MDPOA form to choose a legal medical decision maker increased substantially during the first months of widespread COVID-19 in the state of Colorado. With current increased interest in advance care planning among patients and health care providers, patient portals may be an important tool for advance care planning during the COVID-19 pandemic to enhance and supplement face to face health system advance care planning efforts.

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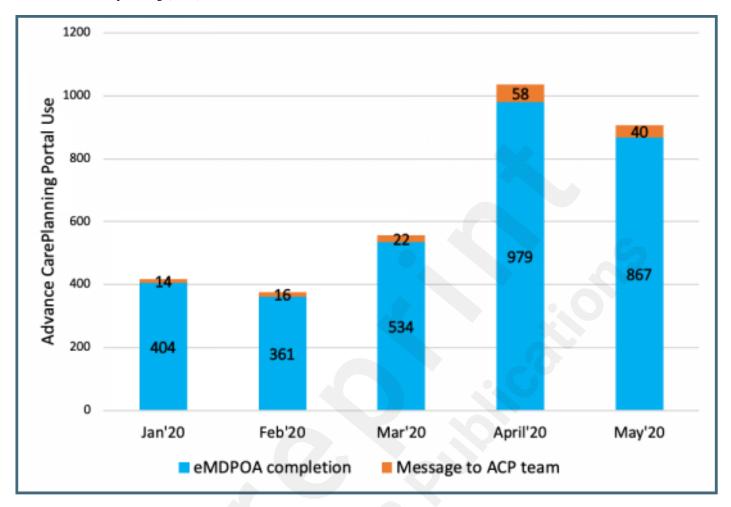
# **Supplementary Files**

# **Figures**

Screenshot of advance care planning patient portal tools webpage, including educational resources, option to send an electronic message about advance care planning, option to submit an electronic Medical Durable Power of Attorney.



Number of patient portal users who submitted an electronic Medical Durable Power of Attorney (eMDPOA) or a message to the advance care planning (ACP) team.



Seven day totals of electronic Medical Durable Power of Attorney (eMDPOA) submissions shown in context of state-wide report of COVID-19 deaths and state-wide policies. On March 26, 2020, the Colorado Governor issued a state-wide stay at home policy. On April 5, Colorado approved Crisis Standards of Care documents.

