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June 17, 2015

United States Senate Committee on Finance  
Chronic Care Working Group  
219 Dirksen Senate Office Building  
Washington, D.C. 20510-6200

**Re: Testimony Submitted to the Senate Committee on Finance Chronic Care Working Group**

Dear Chairman Hatch, Ranking Member Wyden and Senators Isakson and Warner:

Thank you for your leadership on chronic care issues. ADVault, Inc. (ADVault) is pleased to submit the following comments for your consideration as the Chronic Care Working Group of the Senate Committee on Finance moves forward on its work. ADVault, located in Dallas, Texas, is dedicated to ensuring that emergency first responders, doctors, nurses and caregivers always have access to the most important voice in healthcare – yours. Our online service, MyDirectives.com, and our MyDirectives MOBILE™ app, educate and help consumers to complete a digital emergency, critical and advance care plan (ECACP) that includes high-quality advance medical directives. MyDirectives stores completed and signed ECACPs in an encrypted database and uses internationally recognized machine-readable codes, value sets and secure healthcare data transmission standards to ensure that they are accessible to doctors and hospitals 24/7, anywhere in the world. MyDirectives is the world's first completely digital, HIPAA-compliant, emergency, critical and advance care planning platform, delivered as a “meaningful-use” plug-in to electronic health records or as a stand-alone website.

First, we would like to provide the Working Group with some background information on advance care planning (ACP) for American citizens with chronic conditions. Since the adoption of the Patient Self-Determination Act in 1990, Congress and various federal agencies have tried to raise public awareness about advance directives and encourage their adoption and use. Similarly, many states have adopted laws designed to enforce advance directives and educate their citizens about their rights to direct their medical treatment even if they are experiencing a healthcare emergency and cannot effectively communicate with medical personnel or their caregivers.<sup>1</sup> Unfortunately, by 2008 only 18-36% of Americans had completed any form of

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<sup>1</sup> *Advance Directives and Advance Care Planning: Report to Congress*, prepared under contract #HHS-100-03-0023 between the U.S. Department of Health and the RAND Corporation (August 2008). See [http://aspe.hhs.gov/\\_office/specific/daltcp.cfm](http://aspe.hhs.gov/_office/specific/daltcp.cfm).



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advance directive.<sup>2</sup> Moreover, two-thirds of physicians whose patients have advance directives are unaware of the existence of those documents.<sup>3</sup>

In the absence of high-quality ACP, people with chronic conditions are much more likely to receive unwanted, non-beneficial, high-suffering, and high-cost medical interventions if and when they become patients:

- Cancer patients who do not engage in ACP are seven times more likely to be placed on mechanical ventilation and eight times more likely to undergo attempts at resuscitation prior to death;<sup>4</sup>
- In contrast, nursing home patients that engage in ACP have less frequent hospitalization, improved patient and family satisfaction, and 33% lower costs of care;<sup>5</sup> and
- Patients in general who engage in ACP are more likely to receive treatment compatible with their personal values.<sup>6</sup>

This is only an example of the significant published research demonstrating that past approaches to advance care planning have not worked to either improve care or control costs associated with that care. That same research, as well as prior testimony of experts appearing before Congress, the Department of Health and Human Services, and the Office of the National Coordinator for Health Information Technology (ONC), shows that we must normalize emergency, critical and advance care planning in order to be successful. We believe this goal can be achieved, and if members of the Working Group are serious about improving care for our citizens with chronic conditions, we encourage you first and foremost to pursue strategies that will accelerate emergency, critical and advance care planning for all citizens *before* they become chronically ill or before old age and frailty strike.

How can we achieve this goal of improving upon and normalizing the emergency, critical and advance care planning process? ADVault agrees with the Institute of Medicine (IOM), which has recommended the use of technology to address care planning issues. Specifically, in its September 2014 report, “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,” the IOM stated that “electronic storage of advance directives, statements of wishes, health care proxies, or other relevant materials – either in the patient’s electronic health record or an external database – holds promise for solving some current problems with these documents.” Precedent exists for successfully moving from paper-based processes to digital platforms (e.g., electronic preparation and filing of federal tax returns). We

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<sup>2</sup> *Idem* at page 13.

<sup>3</sup> Kass-Bartlemes BL, Hughes R, Rutherford MK, Boches J. *Research in Action Issue #12. Advance Care Planning: Preferences for Care at the End of Life*. Rockville, MD: Agency for Healthcare Research and Quality (AHRQ). Mar 2003; AHRQ Pub No. 03-0018.

<sup>4</sup> B Zhang, AA Wright, ME Nilsson, HA Huskamp, et al. *Associations between advanced cancer patients' end-of-life conversations and cost experiences in the final week of life*. J Clin Oncol. (Meeting Abstracts) May 2008; 26(15), suppl 9530.

<sup>5</sup> DW Molloy, et al. *Systematic Implementation of an Advance Directive Program in Nursing Homes: A Randomized Trial*. JAMA. March 15, 2000; 283(11):1437-1444.

<sup>6</sup> KM Detering, AD Hancock et al. *The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomized Controlled Trial*. BMJ 2010;340:c1345.

strongly recommend that Congress adopt legislation requiring all healthcare stakeholders – payers, providers and vendors – to take the measures necessary to ensure that ECACPs (including high-quality advance directives) are created and stored digitally, and that they are able to be located, retrieved and consulted across the healthcare continuum, regardless of the EHR systems in place within various institutions. Interoperability is critical to using ECACPs and advance directives as a healthcare quality improvement tool. We look forward to working with the Senate Health, Education, Labor and Pensions Committee on this issue in particular as it moves forward on policy recommendations related to the EHR incentive programs and “meaningful use.”

If the objective is to improve the care of chronically ill citizens, we also believe that Congress should encourage the Centers for Medicare and Medicaid Services (CMS) and ONC to create new demonstration programs focused on actually listening to consumers/patients and honoring their goals, preferences and priorities for medical treatment in a healthcare crisis, as opposed to the current programs focused on what happens when providers talk “at” or “to” patients with no bidirectional communication in crisis situations. Research has shown that a lack of bidirectional communication can lead individuals to make conflicting or ambiguous choices, and it can result in providers misinterpreting patient goals, preferences and priorities for medical treatments in a medical emergency.

Your letter dated May 22, 2015, includes increasing care coordination as one of the Working Group’s three main goals. Published research shows that care coordination significantly improves when patient objectives, priorities and preferences serve as the starting point for conversations on patient care, and are not merely treated as a by-product of those conversations. Therefore, we recommend that Congress ask healthcare stakeholders to put greater priority on discovering what individual preferences are, and that it incentivize providers and payers to follow those individual preferences and priorities to the extent medically reasonable (and/or that Congress penalize those providers and payers who do not follow patient preferences and priorities to the extent doing so is medically reasonable).

Your letter also includes incentivizing “the appropriate level of care” for patients living with chronic diseases. As we discuss above, research shows that if the goal is improving care, then the discussion as to what constitutes “the appropriate level of care” should start with what the individual’s goals, preferences and priorities are, not with what providers and payers feel is the best course of action to impose upon the individual. Congress should enact legislation that deems a failure to consult patient preferences and/or follow wishes (to the extent medically reasonable) to constitute unnecessary care and medical error.

With respect to your request for feedback on improvements to Medicare Advantage for patients living with multiple chronic conditions, we recommend Congress incentivize all private payers offering Medicare Advantage plans to follow the lead of certain states like Wisconsin and offer emergency, critical and advance care planning to their covered lives, and require the use of digital platforms that ensure those care plans can be located and retrieved 24/7, anywhere in the world. We would also suggest that either this Work Group or another appropriate Congressional committee convene and hold hearings to gather information on the enforcement of advance care planning regulations that are already on the books. Medicare Advantage plans (42 CFR 128(b)), hospitals (42 CFR 482.13), long-term assisted living centers (42 CFR 483.10(b)(8)) – all of them

are supposed to be doing things with advance directives that they're not doing. Better enforcement could get results. Each of these regulations could also be the subject of rulemaking to update them for the 21st century by requiring the advance directives in question to (1) be electronically stored and available 24/7; and (2) include at the very least all of the elements of a living will, a medical power or attorney, a "do-not-resuscitate" order, and organ donation information, as well as the individual's expressed goals, preferences and priorities for medical treatment in a medical emergency or healthcare crisis if the patient cannot communicate. Regulations could also be updated to remove references to state laws as requirements, which would be in line with the August 2008 Report to Congress recommendation of "substance over form," which has been supported by the American Bar Association, the Joint Commission, and many others.

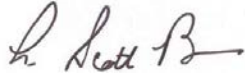
We would also like to comment on your request for options to empower Medicare patients to play a greater role in managing their health and meaningfully engaging with their healthcare providers. We recommend that Congress enact legislation similar to the draft bills currently circulating that would incentivize Medicare beneficiaries to create advance directives and store them in an electronic advance medical directives registry. These bills are based on legislation introduced last Congress by former Senator Coburn and Senator Coons (S. 2240). We also recommend that Congress adopt legislation (and/or require CMS to implement regulations) deeming it unnecessary care and a medical error for a healthcare provider to fail to consult patient goals, preferences and priorities when available, and to follow those wishes to the extent medically reasonable.

Finally, we recommend that Congress address the uncertainty created by differing advance medical directives laws in all 50 states by making it clear that, "in the absence of a valid advance directive (as that term may be defined under the law of a particular state), any authentic expression of a person's medical treatment goals, preferences and priorities, including the naming of a healthcare agent or a similar legal representative, shall be honored by healthcare providers." A bill passed by Congress and signed into law by the Administration that contains this single phrase, which is very similar to the language included in a bipartisan bill introduced in the 113th Congress by Congressman Blumenauer and co-sponsored by 59 Republican and Democrat Representatives (H.R. 1173), would instantly put to rest a longstanding argument and fear that a person's goals, preferences and priorities for medical treatment (including the appointment of a healthcare agent) – even if reduced to writing or some other form of media – might not be honored by medical providers just because those wishes are not on the "right" form, or because the form used doesn't include the "right" legalese or signatures. This small change would have a huge impact on improving care for Medicare patients with chronic conditions.

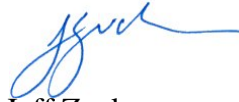
The bottom line is that every American citizen has a right to determine what treatments he or she wants and doesn't want, and that right does not go away just because a person may not be able to communicate as a result of a medical emergency or healthcare crisis. Regardless of what treatments Medicare patients with chronic conditions may choose, medical personnel will operate more efficiently and effectively if they have a better understanding of the values, goals, preferences and priorities of the patients they are treating. We believe that the recommendations we are making today, should Congress choose to follow them, would go a long way in improving healthcare outcomes for every American citizen, not just Medicare patients with chronic conditions.

Thank you again for your leadership on this issue. We look forward to working with you as the Chronic Care Working Group continues this important discussion.

Respectfully submitted,



L. Scott Brown  
President



Jeff Zucker  
Chief Executive Officer