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October 13, 2020

Steven D. Pearson, MD
President
Institute for Clinical and Economic Review
Two Liberty Square, Ninth Floor
Boston, MA 02109

Re: Institute for Clinical and Economic Review—Multiple Myeloma Review Scoping Review

Dear Dr. Pearson,

On behalf of the Cancer Support Community (CSC), we appreciate the opportunity to respond to the request for comments on ICER's scoping review for the treatment of multiple myeloma. Below we are reiterating findings (those that will fit within the three-page limit) from CSC's Cancer Experience Registry Multiple Myeloma Specialty Registry. It is important to take these into account when considering treatments that could alleviate patient burdens as multiple myeloma is a chronic condition that has significant quality of life, logistical, psychosocial, and financial repercussions for many.

Physical Symptoms and Side Effects: 25% of respondents do not report their side effects to their doctor because they do not believe that anything can be done about their side effects of symptoms, however comfort levels with speaking to their doctor about side effects and symptoms were over 99% positive. When asked how often side effects of treatment affect their decisions about treatment for multiple myeloma, 5% said always, 9% said often, and 28% said sometimes. When asked how well respondents felt that their health care team prepared them to manage side effects, 33% said very much, 26% said quite a bit, and 22% said somewhat.

Kidney Disease: 12% of respondents had kidney disease because of their multiple myeloma

Peripheral Neuropathy: 24% of respondents experienced peripheral neuropathy in the past 7 days. 13% of respondents said peripheral neuropathy interfered with their lives very much; 8% said quite a bit; and 16% said somewhat. 7% of respondents said that peripheral neuropathy interfered very much with their ability to participate in social activities; 8% said quite a bit; and 14% said somewhat.

Pain and Bone Pain: 48% of respondents experienced bone pain in the past 7 days. 19% of respondents experienced pain always; 15% experienced pain often; and 25% experienced it sometimes. 13% of respondents said that it interfered with their lives very much; 10% said quite a bit; and 18% said somewhat. 8% of respondents said that pain interfered very much with their ability to participate in social activities; 11% said quite a bit; and 22% said somewhat.

Fatigue: 70% of respondents experienced fatigue in the past 7 days; 20% of respondents experienced fatigue always; 32% experienced it often; and 29% of respondents experienced it sometimes. 16% of respondents said that fatigued interfered with their lives very much; 21% said quite a bit; and 26% said somewhat. 8% of respondents said that fatigue

interfered very much with their ability to participate in social activities; 19% said quite a bit; and 25% said somewhat. **Gastrointestinal Toxicity:** 46% of respondents experienced gastrointestinal toxicity in the past 7 days. 9% of respondents experienced gastrointestinal toxicity always; 18% said often; and 20% said sometimes. 7% of respondents said that gastrointestinal toxicity interfered with their lives very much; 9% said quite a bit, and 15% said somewhat. 2% of respondents said that gastrointestinal toxicity interfered very much with their ability to participate in social activities; 7% said quite a bit; and 12% said somewhat.

Infection: 12% of respondents experienced infection in the past 7 days. Since being diagnosed with multiple myeloma, 31% of respondents were diagnosed with 1-2 infections, 6% were diagnosed with 3-4 infections, and 4% were diagnosed with more than 4 infections. When asked if they were afraid of getting an infection because of their multiple myeloma diagnosis, 10% of respondents said very much, 20% said quite a bit, and 26% said somewhat. **Sleep**

Disturbance: 53% of respondents experienced sleep disturbance in the past 7 days. 10% of respondents experienced sleep disturbance always; 25% of respondents experienced it often; and 30% of respondents experienced it sometimes. 2% of respondents said that sleep disturbance interfered very much with their ability to participate in social activities; 8% said quite a bit; and 18% said somewhat. **Steroids:** 11% of respondents experienced elevated pressure in the eyes (glaucoma) as a result of steroid use. 44% of respondents experienced flue retention, causing swelling in the lower legs as a result of steroid use. 46% of respondents experienced mood swings as a result steroid use. 66% of respondents experienced sleep disturbance as a result of steroid use. 51% of respondents experienced weight gain as a result of steroid use. 14% of respondents said that steroids and their side effects always negatively affect their ability to sleep; 25% said often; and 24% said sometimes. **General Psychosocial Impacts:** When asked how often respondents felt that it would sometimes be better if they were not around, 5% said always, 11% said often, and 17% said sometimes. When asked if they were reluctant to ask for help, 43% of respondents said yes. **Mood Swings:** 31% of respondents experienced mood swings in the past 7 days. 12% of respondents experienced mood swings very much; 24% of respondents experienced it often; and 1% of respondents said sometimes. **Concern about Relapse:**

Regarding the impact of event scale regarding intrusive thoughts about relapse of multiple myeloma, 27% of respondents had such thoughts. **Financial Concerns:** When respondents were asked if they feel upset about money and the cost of care, 19% said always, 23% said often, and 21% said sometimes. When respondents were asked if they feel overwhelmed by the demands of paying for medical care, 8% said always, 19% said often, and 29% said sometimes. When respondents were asked if they are worried that they won't be able to leave any assets to their family when they are gone, 9% said always, 13% said often, and 22% said sometimes. 63% of respondents had received financial assistance related to their multiple myeloma. 55% of respondents said that a member of their health care team talked to them about resources related to getting financial help or financial counseling. When respondents were asked how helpful financial counseling would be for someone with multiple myeloma, 52% said very much, 29% said quite a bit, and 12% said somewhat. When asked if people in the community had donated money to them, 14% of respondents said yes. **Isolation:** When respondents were asked if they feel that they are alone, 9% said always, 22% said often, and 22% said sometimes. When respondents were asked if they feel that they have brought too much hardship on their family, 14% said always, 31% said often, and 24% said sometimes. **Relationships:** When asked how supportive their family is in respect to their cancer, 60% said very much, 25% said quite a bit, and 9% said somewhat. When asked how supportive their friends are in respect to their cancer,

37% said very much, 28% said quite a bit, and 23% said somewhat. When respondents were asked if they feel that they are not being the best spouse/partner they could be, 4% said always, 19% said often, and 19% said sometimes. When respondents were asked if they feel that they are not being the best parent they could be, 8% said always, 20% said often, and 17% said sometimes. When respondents were asked if they feel that they are not being the best friend they could be, 9% said always, 23% said often, and 25% said sometimes. When respondents were asked if their friends do not understand, 10% said always, 22% said often, and 23% said sometimes. When respondents were asked if their family do not understand, 7% said always, 22% said often, and 23% said sometimes. When respondents were asked if they are worried that they will be a burden on their family as their disease progresses, 21% said always, 30% said often, and 19% said sometimes. When respondents were asked if they have had limited contact with friends because of their multiple myeloma, 41% said yes. When respondents were asked if they have had limited contact with family members because of their multiple myeloma, 31% said yes. When asked if they feel like they don't have enough close friends or family members, 25% of respondents said yes. When asked if they have fewer people they can rely on before cancer, 27% said yes. **Work:** When respondents were asked if they were upset because they fall behind at work and others have to fill in, 4% said always, 9% said often, and 15% said sometimes. When respondents were asked if they have forgone a job opportunity or career advancement because of multiple myeloma, 40% said yes. **Treatment Decision Making:** When respondents were asked if they feel they had a choice about where to receive medical treatment for multiple myeloma, 82% said yes. When respondents were asked how much of an impact the distance from home had on deciding where to seek medical treatment, 20% said very much, 17% said quite a bit, and 16% said somewhat. When respondents were asked how much of an impact had insurance coverage or cost had on deciding where to seek medical treatment, 33% said very much, 17% said quite a bit, and 12% said somewhat. When respondents were asked how much of an impact the sense of trust or familiarity with the doctor or the practice had on deciding where to seek medical treatment, 39% said very much, 22% said quite a bit, and 12% said somewhat. When respondents were asked how much of an impact the experience of specialization of the physician had on deciding where to seek medical treatment, 55% said very much, 24% said quite a bit, and 5% said somewhat. When respondents were asked how much of an impact access to clinical trials had on deciding where to seek medical treatment, 17% said very much, 8% said quite a bit, and 16% said somewhat. Recent research from CSC also shows that, among patients with multiple myeloma, poorer physical function and greater symptom burden are associated with worse depression, anxiety, and social satisfaction (Zaleta et al., 2020), underscoring the critical connection between patients' experience of burden and their quality of life. In closing, thank you for the opportunity to submit these comments. If we can serve as a resource, please reach out to me at Efranklin@cancersupportcommunity.org.

Sincerely,



Elizabeth Franklin, PhD, MSW
Executive Director, Cancer Policy Institute
Cancer Support Community Headquarters