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Statement by Myrl Weinberg
President, National Health Council
to the
Federal Coordinating Council for Comparative Effectiveness
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Good afternoon. My name is Myrl Weinberg and I'm the president of the National Health Council.

The National Health Council provides a united voice for people with chronic diseases and disabilities and their family caregivers. On behalf of the more than 125 million Americans living with chronic conditions, the NHC is encouraged about the opportunity to foster a more effective, safe, efficient, and affordable health care system.

In order to achieve these aims, the NHC believes comparative effectiveness research ***must*** address the needs and life circumstances of individual patients.

Guided by the principles of evidence-based medicine, as defined by Dr. David Sackett, CER must integrate clinical expertise with the best evidence ***and*** individual patients' predicaments, rights, and preferences to support making the best health care decisions.

Please note that I talk about patients, not consumers. Nearly 40 percent of the population in this country has a chronic disease or disability. These individuals are different from the average consumer, who seeks a "healthier lifestyle." The NHC agrees strongly that prevention must be a core element in any comprehensive health plan. However, people with chronic conditions seek answers that will provide a chance for a more normal life, a possibility to live longer and feel better.

We want to stress three points today:

1. **The comparative effectiveness research agenda must include health care delivery issues, such as the organization, design, and management of patient care.** CER should supply us with good evidence about what works and what doesn't. However, it should not be just about one product against another, or treatment process, or combination thereof. We need to know how people with chronic conditions can live longer and better, and how health care can meet their unique personal needs and life circumstances.

2. **Patients need a defined role in CER.** To ensure that patients have a meaningful voice equivalent to other stakeholders, we need both a transparent process and a

venue for patient voices to be heard. Additionally, all stakeholders, including patients, should be involved in disseminating comparative effectiveness research findings.

3. **CER results must not drive de facto coverage or reimbursement recommendations until they are evaluated in "real world' settings to determine their impact on individuals and various subpopulations.** We need to disentangle – at least in the beginning – the findings of good CER from coverage or reimbursement decisions. We need to break the immediacy of that relationship in order to avoid denial of appropriate care.

As part of its health policy procedures, the NHC conducts nationwide, telephone focus groups with patients, and their greatest concern is that CER will be used inappropriately to deny access or to funnel them into a "one size fits all" mode of care.

Working together, we have an opportunity to craft a CER agenda that has the potential to improve health care delivery to achieve the highest benefit possible for both individual patients and society.

Thank you.