



A TOOLKIT FOR COMPENSATING PATIENTS AND PATIENT GROUPS FOR THEIR EXPERT INPUT

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A US nonprofit organization founded in 1920, the National Health Council (NHC) brings diverse organizations together to forge consensus and drive patient-centered health policy. The mission of the NHC is to provide a united voice for the more than 160 million people in the US with chronic diseases and disabilities, and their family caregivers. Made up of more than 130 US health-related organizations and businesses, the NHC's core membership includes 60 leading US patient organizations, which control its governance and policy-making process. Other members include health-related nonprofit associations and organizations including the provider, research, and family-caregiver communities, and businesses representing biopharmaceutical, device, diagnostic, generic, and payer organizations.

Over the last few years, patient-organization and industry NHC members have frequently asked for assistance and tools to determine appropriate policies for compensating patients, patient organizations, and family members for patient-engagement activities. Tools, such as fair-market-value (FMV) calculators are often used by industry to ensure compensation rates used when engaging doctors, researchers, and other outside experts are competitive and compliant with regulations. But, methods for calculating clinician and researcher rates are not appropriate for setting rates for patients involved in patient-focused drug development. Similarly, members of the patient community rarely have the resources to review lengthy, jargon-laden legal contracts.

To meet this member need, the NHC initiated in 2018 a project with the goal to ensure all stakeholders confidently enter into compliant, and sustainable engagement efforts to effectively drive health care innovation based on patient insights in a trusted and quality manner. The purpose of this session is to describe the initiative, processes and methods undertaken, status, and deliverables, and to share information about lessons learned and next steps for the future. The project objective is to grow resources that support engagement between industry stakeholders and the patient community as part of medical-product development. To date, these resources include:

1. Developing a fair-market-value (FMV) calculator for compensating patients/caregivers and patient groups
2. Adapting international conflict-of-interest and privacy principles for use in the U.S. (i.e., PFMD/WECAN project)
3. Adapting international contract templates for use in the U.S. (i.e., PFMD/WECAN project)

An interactive component will include two topics for group discussion:

1. The NHC FMV Calculator Patient Engagement Activities lists will be provided. These lists are considered living documents and are inputs to the FMV. Participants will be asked to discuss and provide input on the activities lists.
2. With any project such as this, unforeseen challenges RE encountered. As a second topic for interactive discussion, challenges still to be resolved will be posed to the group for brainstorming potential solutions.