



NATIONAL HEALTH COUNCIL

# NHC Fair-Market Value Calculator

## Glossary of Terms

You will notice that by hovering over the information icon ⓘ throughout the Calculator, a definition for that term will appear. For your convenience, the definitions are also included in this document.

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## Participant Type

- **Individual Patient:** A person living with a condition or with a known risk for getting a condition who can speak to their individual/personal experiences with the disease and related treatments, if applicable. May or may not be affiliated with a patient organization but is not speaking on behalf of a patient organization. Payment for the engagement is made directly to the individual (or payment is through a third party to the patient).

### *Type of Individual Patient*

- **Patient with condition with confirmed diagnosis:** Diagnosis has been confirmed by a qualified health care professional.
- **Patient with condition, self-reported diagnosis:** Diagnosis is self-reported.
- **Patient at risk for the condition:** Does not yet have the condition, but is at risk for the condition (e.g., genetic testing, family history).
- **Patient in remission/cured:** Previously underwent treatment for disease, currently no signs of active disease (definition of remission may be disease specific).

### *Treatment Experience*

- **Treatment Experience** (Yes, No, N/A): Patient has firsthand experience with a drug or other intervention for the disease. The experience may be in the past or ongoing.
- **Caregiver:** A person that can speak to their individual/personal experience as a non-professional, non-paid caregiver of someone with a condition. This person may or may not also be a family member. Payment for the engagement is made directly to the individual.
- **Family Member:** A person who is a family member, related to the individual with the illness (e.g., sibling, parent), who can speak to their personal experience living with someone with the condition. Payment for engagement is made directly to the individual.



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- **Patient Group Representative:** An individual employed by a patient organization, typically a nonprofit group that focuses on a condition and/or advocates on behalf of patients. Payment for engagement is made typically to the employer organization, not the individual (please see our Compensation Principles for more details).
  - **Senior Leader** (Yes, No): Does the Patient Group Representative have experience as a senior leader in a patient organization (e.g., CEO, CMO, VP).

## Expertise Required for this Engagement

- **Living with or at risk for the condition:**
  - Personal/individual experience living with a known risk for a condition.
  - Personal/individual experience living with a condition and associated treatments.
  - Personal/individual experience caring for someone with the condition and associated treatments.
  - Personal/individual experience living with someone with the condition and associated treatments.
  - People who have this expertise may say:
    - I experienced...
    - The person I provide care for experienced...
- **Knowledge about the condition beyond individual/personal experience:**
  - Knowledge, experience, or expertise on the entire population, subpopulations, and/or subgroups in terms of experiences and other characteristics.
  - People who have this expertise may say:
    - People who have this illness typically experience...
- **Subject Matter Expert:**
  - Expertise on a specific subject such as clinical trials, epidemiology, policy, reimbursement, etc., gained through lived, career experience, or formal training.
  - Expert/experienced facilitator.
- **Skilled in Public Speaking:**
  - Experience with speaking engagements, addressing small or large groups, addressing the media, facilitation, etc.



## Activity Time Definitions – Individual Patient, Caregiver, and Family Member

- **Co-Creation:** Provide consultation to develop, review, and edit or provide input to generate documents (e.g., interview guide(s), inclusion/exclusion criteria, survey, report, manuscript).
- **Presentation/Speaker – Conference, Roundtable, Symposium, or Panel:** Speaking as an expert at a medium- to large-size gathering, typically with a scientific or policy theme, or speaking for a short period as part of a small group (2 or more) of presenters; typically each speaker addresses the same topic from various perspectives
  - **Note:** Audience size and type of a presentation can impact the amount of preparation time needed, e.g., someone giving a keynote presentation to a large audience would be expected to require more preparation time than someone giving a brief testimonial on their experiences before a small group.
- **Presentation/Speaker – Keynote:** Provide an extended speech, as the sole speaker, on a thematic topic. Typically, the opening, luncheon, or closing speaker.
- **Presentation/Speaker – Testimonial:** Speak to personal experience; typically, a short presentation to a small- or medium-size group.
- **Mock trial participant:** Walk through the experience of being part of a clinical trial protocol.
- **Interview Participant:** Take part in a one-on-one interview. Typically includes a trained interviewer who follows a discussion guide.
- **Focus Group Participant:** Participate in an organized focus group with other participants. Typically includes a trained facilitator who follows a discussion guide.
- **Survey Responder:** Answer a set of standard questions in a questionnaire.
- **Reviewer:** Reviews documents/materials to provide input, critique, suggestions, edits, etc.
- **Pre-Activity Research:** Assisting an organization with research or a scoping review prior to an engagement activity.
- **Chair or Co-Chair an Advisory Board or Governance Board:** Facilitate discussions and provide thought leadership to advance an initiative or project.



- **Member of an Advisory Board or Governance Board:** Participate as an invited expert to provide input on a set topic or questions or to oversee conduct of a project, organization, etc.
- **Roundtable Participant:** Participate as an invited expert (or thought leader) in a small group gathering to provide input on a set topic or questions (invited as a participant, not a speaker),
- **Recruitment for a Study, Trial, or Other Engagements:** Time to recruit patients for an engagement activity or match making (recruiting) with other patient advocates or a patient advocacy group.
  - **Note:** Consider time dedicated to recruiting patients who ultimately decline to participate, or do not meet eligibility criteria. Time also may be affected by the rarity of the disease.
- **Be Shadowed in Daily Life by a Researcher:** Allow a researcher to follow the patient/family member throughout a typical day to understand daily life with a condition.
- **Communications/Awareness Campaign Collaboration:** Support communication of information to patients/families on a health topic through non-branded, co-developed newsletters, blogs, social media, webinars, etc.
  - Note: Communication of branded information would be considered marketing and not engagement.
- **Other:** Any other engagement activity not listed above.

## Activity Time Definitions – Patient Group Representatives

- **Pre-Engagement Planning:** Staff time to participate in pre-engagement planning meetings.
- **Co-Creation:** Staff time to develop, review, and edit or provide input to generate documents (e.g., interview guide(s), inclusion/exclusion criteria survey, report, manuscript).
- **Presentation/Speaker – Conference, Roundtable, Symposium, or Panel:** Speaking as an expert at a medium- to large-size gathering, typically with a scientific or policy theme, or speaking for a short period as part of a small group (2 or more) of presenters; typically each speaker addresses the same topic from various perspectives.



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- **Presentation/Speaker – Testimonial:** Speak to personal experience; typically, a short presentation to a small- or medium-size group.
- **Pilot Testing:** Staff time to recruit several patients and to test a data collection tool (e.g., interview guide, survey) with them.
- **Eligibility Screening:** Pre-screen of patients for an engagement activity for an organization.
- **Facilitate Interview with Patient Group Member:** Staff time to facilitate an interview utilizing a prepared discussion guide.
- **Facilitate Focus Group with Patient Group Member:** Staff time to facilitate a focus group utilizing a prepared discussion guide.
- **Contribute to Data Analysis:** Staff time dedicated to analyzing or synthesizing data including patient registries.
- **Interpretation:** Staff time dedicated to interpreting or placing findings in context.
- **Community Review:** Dissemination of a policy, document, etc. to patients or patient advocate community in order to receive critiques or approval.
- **Dissemination:** Staff time to support communication and dissemination activities.
- **Collect Additional Registry Data:** Staff time to make changes to an already existing registry. May include time to change databases, outreach to patients to answer new questions, etc.
- **Provide Cuts of Registry Data for Analysis:** Staff time to create de-identified analytic files someone else can use to conduct analysis.
- **Conduct a Membership Survey:** Staff time to co-develop survey materials, identify candidates, send the survey, conduct follow-up, collect data, analyze the data, prepare a report, and present findings.



- **Reviewer:** Reviews documents/materials to provide input, critique, suggestions, edits, etc.
- **Pre-Activity Research:** Assisting an organization with research or a scoping review prior to an engagement activity.
- **Chair or Co-Chair an Advisory Board or Governance Board:** Facilitate discussions and provide thought leadership to advance an initiative or project.
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  - Note: Communication of branded information would be considered marketing and not engagement.
- **Other:** Any other engagement activity not listed above.

## Other Modifiers

- **Risk or Liability (e.g., legal or financial):** The activity places the participant at some level of risk, in terms of their responsibility (e.g., member of a data safety monitoring board).



- **Wages Lost:** Since the individual is being compensated for their time commitment for the activity, it would be unusual to compensate them for wages lost. However, this might be a consideration if it impacts recruitment of representative target population. This should be considered on a case-by-case basis.
- **Care Support (e.g., Childcare or Eldercare Needed):** To ensure representativeness of a target population, it may be necessary to offer care reimbursement for a dependent. This should be considered on a case-by-case basis.
- **Size of Patient Organization:** The size of the organization may also be a factor to consider on a case by case basis.
- **Urgency (e.g., Short Time to Prepare):** The activity is expected to be completed within a very short turnaround time period, e.g., the individual is expected to quickly arrange travel, send feedback on materials, or create something for a third party, etc. with a very short deadline.