



## Patient Activities Framework

This document is a guide to gathering the data and assumptions necessary to use the fair-market value calculator. It assumes the individual using the tool has clearly defined the specific need for which patient or patient organization engagement is desired and that the type and scope of the activity, expertise required to perform the activity, and type of participant have been considered. This document will help align those factors to the definitions and descriptors that drive the inputs in the fair-market value calculator. For new activities, this document can also serve as a tool to help to ensure the engagement need is clearly articulated in advance.

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## TYPE OF PARTICIPANT

Begin by describing the type of participant you would like to engage. This could include a patient, caregiver/family member or patient-organization staff member.

#1 - Type of Participant	
Type of Patient/Caregiver/Family Member/Representative	Definitions/Descriptors
<b>Individual Patient</b>	<p><i>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.</i></p> <p><i>May or may not work for or be affiliated with a patient organization. However, would not be speaking on behalf of a patient organization.</i></p> <p><i>Payment for the engagement is made directly to the individual (or payment is through a third party to a patient).</i></p>
1. Select the type of individual patient	
Patient with condition with confirmed diagnosis	<i>Diagnosis has been confirmed by a qualified health care professional.</i>
Patient with condition, self-reported diagnosis	<i>Diagnosis is self-reported.</i>
Patient at risk for the condition	<i>Does not yet have the condition but is at risk for the condition (e.g., genetic testing, family history).</i>
Patient in remission/cured	<i>Previously underwent treatment for disease, currently no signs of active disease (specific definition of remission may be disease-specific).</i>
2. Select any specific characteristics needed (select all that apply)	
Treatment experience (Yes, No, N/A)	<i>Patient has firsthand experience with a drug or other intervention for the disease. The experience may be in the past or ongoing.</i>

## #1 - Type of Participant, cont.

<p><b>Caregiver</b></p>	<p><i>A person that can speak to their individual/personal experience as a non-professional, non-paid caregiver/ of someone with a condition.</i></p> <p><i>This person may or may not also be a family member.</i></p> <p><i>Payment for the engagement is made directly to the individual.</i></p>
<p><b>Family Member</b></p>	<p><i>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.</i></p> <p><i>Payment for the engagement is made directly to the individual.</i></p>
<p>1. Select the type of caregiver/family member</p>	
<p>For a patient with condition with confirmed diagnosis</p>	<p><i>Patient cared for has a diagnosis that has been confirmed by a qualified healthcare professional.</i></p>
<p>For a patient with condition, self-reported diagnosis</p>	<p><i>Patient cared for has a diagnosis that is self-reported.</i></p>
<p>For a patient at risk for the condition</p>	<p><i>Patient cared for does not yet have the condition but is at risk for the condition (e.g., genetic testing, family history).</i></p>
<p>For a patient in remission/cured</p>	<p><i>Patient previously underwent treatment for disease, currently no signs of active disease (specific definition of remission may be disease-specific).</i></p>

## #1 - Type of Participant, cont.

	<p><i>An individual employed by a patient organization, typically a nonprofit group that focuses on a condition and/or advocates on behalf of patients.</i></p> <p><i>Payment for engagement is made typically to the employer organization, not the individual (please see our Compensation Principles for more details).</i></p>
For patient, with the condition	<p><i>Can speak to individual/personal treatment experiences</i></p>
Patient advocacy experience	<p><i>Works for a patient organization, but is not in a leadership role</i></p>
Patient advocacy senior leadership experience	<p><i>Has experience as a senior leader in a patient organization (e.g., CEO, CMO, VP)</i></p>

## EXPERTISE REQUIRED

Indicate here the skill set required for the activity. One or more descriptor may be selected.

#2 - Expertise Required	
Expertise	Definitions/Descriptors
Living with or at risk for the condition:	<ul style="list-style-type: none"> <li>• <i>Personal/individual experience living with a known risk for a condition</i></li> <li>• <i>Personal/individual experience living with condition and associated treatments</i></li> <li>• <i>Personal/individual experience caring for someone with the condition and associated treatments</i></li> <li>• <i>Personal/individual experience living with someone with the condition and associated treatments</i></li> </ul>
Knowledge about the condition beyond individual/personal experience:	<ul style="list-style-type: none"> <li>• <i>Knowledge, experience, or expertise on the entire population, subpopulations, and/or subgroups in terms of experiences and other characteristics</i></li> <li>• <i>People who have this experience may say:</i> <ul style="list-style-type: none"> <li>○ <i>People who have this illness typically experience...</i></li> </ul> </li> </ul>
Subject Matter Expert:	<ul style="list-style-type: none"> <li>• <i>Expertise on a specific subject such as clinical trials, epidemiology, policy, reimbursement, etc. gained through lived, career experience, or formal training.</i></li> <li>• <i>Expert/experienced facilitator</i></li> </ul>
Skilled in Public Speaking:	<ul style="list-style-type: none"> <li>• <i>Experience with speaking engagements, addressing small or large groups, addressing the media t, facilitation, etc.</i></li> </ul>

## TYPE OF ACTIVITY

In this section, indicate the type of activity the participant is being asked to take part in.

#3 - Type of Activity (Individual)	
Type of Activity	Definitions/Descriptors
Co-Creation	<i>Provide consultation to develop, review and edit or provide input to generate documents (e.g., interview guide(s), inclusion/exclusion criteria, survey, report, manuscript).</i>
Presentation/speaker	
Testimonial	<i>Speak to personal experience; typically, a short presentation to a small or medium size group</i>
Keynote	<i>Provide an extended speech, as the sole speaker, on a thematic topic. Typically, the opening, luncheon, or closing speaker</i>
Panel	<i>Speak 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</i>
Conference/Roundtable/ Symposium speaker	<i>Speaking as an expert at 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</i>
	<i>Note: Audience size and type of presentation can impact the amount of preparation time needed (See #4). 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.</i>
Mock Trial Participant	<i>Walk through the experience of being part of a clinical trial protocol</i>
Interview participant	<i>Take part in a one-on-one interview. Typically includes a trained interviewer who follows a discussion guide.</i>

Focus group participant	<i>Participate in an organized focus group with other participants. Typically includes a trained facilitator who follows a discussion guide.</i>
Survey responder	<i>Answer a set of standard questions in a questionnaire</i>
Reviewer	<i>Reviews documents/materials to provide input, critique, suggestions, edits, etc.</i>
Pre-activity Research	<i>Assisting an organization with research or a scoping review prior to an engagement activity</i>
Chair or Co-Chair an Advisory Board or Governance Board	<i>Facilitate discussions and provide thought leadership to advance an initiative or project</i>
Member of an Advisory Board of Governance Board	<i>Participate as an invited expert to provide input on a set topic or questions or to oversee conduct of a project, organization, etc.</i>
Roundtable Participant	<i>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).</i>
Recruitment for a study, trial or other engagement	<i>Time to recruit patients for engagement activity or match-making (recruiting) with other patient advocates or a patient advocacy group. (Note: Must 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).</i>
Be shadowed in daily life by a researcher	<i>Allow a researcher to follow the patient/family member throughout a typical day to understand daily life with a condition</i>
Communications/ awareness campaign collaboration	<i>Support communication of information to patients/families on a health topic through non-branded, co-developed newsletters, blogs, social media, webinars, etc.</i>  <i>Note: Communication of branded information would be considered marketing and not engagement</i>
<b>Other</b>	<i>Any other engagement activity not listed above.</i>

### #3 - Type of Activity (Patient Group-Specific)

Type of Activity	Definitions/Descriptors
Pre-Engagement Planning	<i>Staff time to participate in pre-engagement planning meetings</i>
Co-Creation	<i>Staff time to develop, review, and edit or provide input to generate documents (e.g., interview guide(s), inclusion/exclusion criteria, survey, report, manuscript).</i>
Presentation/speaker Testimonial  Keynote  Panel  Conference/Roundtable/ Symposium speaker	<p><i>Speak to personal experience; typically, a short presentation to a small- or medium-size group</i></p> <p><i>Provide an extended speech, as the sole speaker, on a thematic topic. Typically, the opening, luncheon, or closing speaker</i></p> <p><i>Speak 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</i></p> <p><i>Speaking as an expert at 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</i></p> <p><i>Note: Audience size and type of presentation can impact the amount of preparation time needed (See #4). 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.</i></p>
Pilot testing	<i>Staff time to recruit several patients and to test a data collection tool (e.g., interview guide, survey) with them</i>
Eligibility Screening	<i>Pre-screen of patients for an engagement activity for an organization</i>
Facilitate Focus Group with Patient Group Member	<i>Staff time to facilitate a focus group utilizing a prepared discussion guide.</i>



Facilitate Interview with Patient Group Member	<i>Staff time to facilitate an interview utilizing a prepared discussion guide.</i>
Contribute to data analysis	<i>Staff time dedicated to analyzing or synthesizing data including patient registries.</i>
Interpretation	<i>Staff time dedicated to interpreting or placing findings in context.</i>
Community Review	<i>Dissemination of a policy, document, etc. to patients or patient advocate community in order to receive critiques or approval</i>
Dissemination	<i>Staff time to support communication and dissemination activities</i>
Collect additional registry data (e.g., add questions)	<i>Staff time to make changes to an already existing registry. May include time to change databases, outreach to patients to answer new questions, etc.</i>
Provide cuts of registry data for analysis	<i>Staff time to create de-identified analytic files someone else can use to conduct analyses.</i>
Conduct analyses of survey or registry data	<i>Staff time to prepare an analytics plan, create analytic files, conduct the analysis, prepare a report, present findings</i>
Conduct a membership survey	<i>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</i>
Reviewer	<i>Reviews documents/materials to provide input, critique, suggestions, edits, etc.</i>
Pre-activity Research	<i>Assisting an organization with research or a scoping review prior to an engagement activity</i>
Chair or Co-Chair an Advisory Board or Governance Board	<i>Facilitate discussions and provide thought leadership to advance an initiative or project</i>
Member of an Advisory Board or Governance Board	<i>Participate as an invited expert to provide input on a set topic or questions or to oversee conduct of a project, organization, etc.</i>
Roundtable Participant	<i>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)</i>
Recruitment for a study, trial or other engagements	<i>Staff time to recruit patients for engagement activity or match-making (recruiting) with other patient advocates or a patient advocacy group. (Note: Must consider time dedicated to recruiting patients who ultimately decline to</i>

	<i>participate or do not meet eligibility criteria. Time also may be affected by the rarity of the disease)</i>
Communications/awareness campaign collaboration	<i>Staff time to 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</i>
Other	<i>Any other engagement activity not listed above</i>

## INTERACTION MODE

In this section, indicate the method(s) by which the participant will perform the activity.

#4 – Interaction Mode	
Mode of interaction	Definitions/Descriptors
(check all that apply) In person Telephone Virtual Meeting Web-based Activity (i.e., online survey) Paper-based/mail Other	<i>The method(s) by which the participant will perform the activity. e.g., interview by telephone or in-person; focus group by videoconference or in-person.</i>

## TIME COMMITMENT

In this section, indicate the time commitment that will be required by the participant.

### #5 - Time Commitment

**Preparation time** expected (may be none):

*Total number of hours expected for preparation* \_\_\_\_

Please describe preparation activities, if any: (e.g., reading materials, watching a video, completing questionnaires, planning or preparation meetings, etc.). Note this can also include post-activity engagement such as a debrief.

**Activity time** expected per event:

Hour(s) \_\_\_\_

Frequency:

Single event, one time only

More than one event, number of events \_\_\_\_ per day/week/week/month/year

**Post-Activity Time expected (may be none):**

*Total number of hours expected for post activity* \_\_\_\_

Please describe activities, if any: (e.g., debrief call, submit an evaluation, etc):

Expected **total** number of events/interactions: \_\_\_\_

Expected total number of hours for all events and all activities: \_\_\_\_ (= total preparation + total activity + post activity time)

If travel is required, estimated total travel time (hours): \_\_\_\_

Time entered should equate to travel time determined under Section 6, Travel Considerations.

## TRAVEL CONSIDERATIONS

In this section, indicate the amount of travel expected and travel requirements. Note, where the participant might be expected to do some parts electronically and some in-person, indicate both.

#6 – Travel Considerations	
Travel	Definitions/Descriptors
No travel expected	<i>No travel is required, e.g., telephone, web interaction</i>
Travel is expected	<i>Face-to-face activity that requires travel</i>
Local travel  Total estimated travel time Minutes        _____ Hours            _____	<i>Local ground travel by car, bus, subway or train is required. Typically, no more than 2 hours each way (1 to 200 miles) would be considered local travel. However, the patient’s condition and individual condition must be considered on a case-by case basis to determine if they need additional support for extra travel time. Local travel might also include the travel to get to the airport or train station for long distance travel.</i>  <i>Mileage            _____</i> <i>Tolls                _____</i> <i>Parking            _____</i>
Long-distance travel	<i>Ground travel over 2 hours each way required, e.g., a long drive or train ride, or air travel is expected.</i>  <i>Distance: 201 to 500 miles</i> <i>Hours: 4</i>  <i>Distance: 501 to 1500 miles</i> <i>Hours: 6</i>  <i>Distance: Over 1500 miles</i> <i>Hours: 8</i>  <i>Train or airplane    _____</i>

Total estimated travel time Hours _____ Days _____	<i>Hotel</i> _____ <i>Incidentals</i> _____
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**#6 – Additional Travel Requirements**

<ul style="list-style-type: none"> <li>• Additional Travel Requirement (Select all that apply): A caregiver must accompany</li> <li>• Accompanying medical equipment (e.g., wheelchair, oxygen tank, etc.)</li> <li>• Travels with a service animal</li> <li>• An additional 1-2 days of travel needed due to condition</li> <li>• Special dietary requirements</li> <li>• Rest breaks needed</li> <li>• Other</li> </ul>	
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## OTHER POTENTIAL MODIFIERS

Indicate here other potential modifiers that could have an impact on compensation or reimbursement

<b>#7 - Other Modifiers</b>	
<b>Other Modifiers (Select all that apply):</b>	<b>Definitions/Descriptors</b>
Risk or liability (e.g., legal or financial)	<i>The activity places the participant at some level of risk in terms of responsibility (e.g., member of a data safety monitoring board)</i>
Wages Lost	<i>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.</i>
Care Support (e.g., Childcare or Eldercare Needed)	<i>To ensure representativeness of a target population, it may be necessary to care reimbursement for a dependent. This should be considered on a case-by-case basis.</i>
Size of Patient Organization	<i>The size of the organization may also be a factor to consider on a case-by-case basis.</i>
Urgency (e.g., Short Time to Prepare)	<i>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.</i>