Welcome to the Patient Engagement Open Forum virtual session

Patient Engagement Open Forum is a series of virtual events (in 2020) where we will work together, in a multi-stakeholder context, **to turn patient engagement from an aspiration into reality**.

The Forum aims to provide a **holistic perspective** of patient engagement, the **landscape and actors**, and **foster collaboration** and **co-creation** while **breaking down fragmentation** that are often present in patient engagement work.
Patient Engagement Open Forum Agenda in 2020

**June 25th**
P EOF2020 opening plenary (PARADIGM, PFMD and EUPATI)

Parallel sessions:
- Patient Engagement tools session #1 (consultation organised by PARADIGM)
- Patient engagement within MedTech (panel organised by EUPATI)
- Patient experience in regulatory processes (workshop organised by PFMD)

**June 26th**

Parallel sessions:
- How to engage patients in the early phases? (workshop organised by PFMD)
- Patient engagement in co-creating plain language summaries (workshop organised by PFMD)

**July 9th**

Parallel sessions:
- Patient Engagement tools session #2 (consultation organised by PARADIGM)
- Flash presentations
  1. Sustainability roadmap for the patient engagement ecosystem
  2. Patient engagement agreements explained
  3. Patient engagement in medicines R&D in the CEE region
- Motherhood should not be a fight – better safety information on medicines use during pregnancy and breastfeeding, with patients for patients. (Workshop organised by IMI-Conception)

**September 10th**

Plenary session
- PARADIGM Patient Engagement Toolbox (webinar organised by PARADIGM)
- Patient Engagement Monitoring and Evaluation Framework (workshop organised by PARADIGM)

**September 24th**

Parallel sessions:
- How PE can foster access through improved affordability? (webinar organised by EUPATI)
- Patient engagement in clinical trial phase 0 and in the regulatory submission phase (workshop organised by PFMD – to be confirmed at a later date)
- From diagnosis to treatment and beyond: personalised medicine – what’s in it for patients and how to make it available to patients who could benefit from it? (workshop supported by PFMD)

**October 15th**

Parallel sessions:
- Patient Engagement and Quality by Design: Co-Developing an Implementation Roadmap for Clinical Trials (organised by CTTI)
- Good Lay Summary Practice, communicating trial results to the general public – How patient engagement can work (organised by EFPIA and EFCCP)

**November 5th**

Theme: Regulatory

**November 23rd**

Plenary session:
- EOF2020 conclusion session

Eleanor Perfetto, PhD, MS & Silke Schoch
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Background
Why Create an FMV Calculator?

- Patient group and industry member feedback
- Methods and inputs for determining appropriate rates for clinicians and researchers not applicable for patients
Transatlantic Collaboration

Ensuring alignment between the NHC FMV Project and PFMD & WECAN projects:

- Representation on the Steering Committee
- Adapt deliverables
Methods
Developing the FMV Calculator

Define the breadth of activities to be captured in the calculator

Market compensation data for positions requiring similar skills

Compare/reconcile US market rates collected from NHC member organizations

Guidance from a multi-stakeholder Steering Committee

Easy to use, No expensive or proprietary software

Input from PFMD and WECAN partner projects
Getting FMV Right

FMV Input

**EUROPE**
- Patient Survey
- Extension to other stakeholders
- Patient Think Tank
- Guiding Principles
- PE Activity List
- Legal Contract Input
  - Guiding Principles + Contract Template

**USA**
- FMV Patient Compensation Principles
- FMV Calculator
- US Reference Contracts

**Plan European version and roll out**

How to bring to Europe:
- WECAN
- efpiA

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Methods for Estimating FMV Hourly Rates for Patients

- FMV hourly rates for patients should reflect:
  - Types of **activities** for which the patients are engaged
  - **Experience and skills** expected to perform those activities
- Methods need to clearly exclude any potential influence a patient may have on the purchase of the engaging party’s products
- Rates are using annual market compensation as the base, adjusted to a “consulting” rate
- Historical market payments to patients
  - Are considered
  - But, not directly relied upon as there is no insight into how they were determined
Process for Developing FMV Hourly Rates for Patients

1. **Determine Patient Activities:**
   - Breadth and depth determined through
     - PFMD Survey
     - Stakeholder interviews
     - Steering and Review Committee input

2. **Identify Appropriate Benchmarking Compensation Data (in US):**
   - No directly comparable compensation benchmarking data for “patients”
   - Benchmark compensation used for positions requiring similar experience, knowledge, and skills, such as:
     - Hospital patient representatives
     - Marketing positions
     - Research Positions
     - Health Educators
   - National income averages are considered as a reasonableness check
Estimating FMV Hourly Consulting Rates for Patients

• Estimate an Hourly Consulting Rate:
  ◦ Benchmark annual compensation adjusted to reflect that the patient is providing independent consulting services
  ◦ A consulting rate will include salary, benefits, overhead, and profit based on market data
  ◦ Total annual fair-market compensation is converted to an hourly rate by dividing by the number of work hours in a year
    ▪ The standard number of work hours in the U.S. is 2,080, which is adjusted to exclude holidays and vacation

• A range of rates is developed
National Health Council
Patient Engagement
Compensation Toolbox
NHC Patient Engagement Compensation Toolbox

Patient Engagement Activities Framework

Fair-Market Value Calculator and Resources

Principles for Compensation
Principles for Compensating Patients for Engagement Activities
Principles for Compensating Patients for Engagement Activities

- Type of Patient Engagement Participant
- General Compensation Principles
- Administrative/Logistical Principles
- Time Commitment
- Travel and Reimbursement Considerations
- Declining Compensation
- Other Considerations

Example:

Reimbursement for travel or other expenses required to participate in an activity should be viewed as separate and distinct from compensation, as the reimbursement represents expenses incurred by the patient that would not otherwise be incurred.
Patient Engagement Activities Framework
Patient Engagement Activities Framework

INPUTS AND MODIFIERS

Type of Participant ........................................................................................................... 2
Expertise Required ........................................................................................................... 6
Type of Activity ................................................................................................................ 7
Interaction Mode ............................................................................................................. 11
Time Commitment .......................................................................................................... 12
Travel Considerations ..................................................................................................... 13
Other Potential Modifiers .............................................................................................. 15
Patient Engagement Activities Framework (1/3)

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.

Ex. Individual Patient
- Confirmed diagnosis
- Treatment experience

Ex. Knowledge about the condition beyond individual/personal experience

Ex. Presentation/speaker
- Keynote

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

Indicate the type of activity the participant is being asked to take part in.
Patient Engagement Activities Framework (2/3)

Indicate the mode of interaction.

Ex. In-person and teleconference

Indicate time commitment that will be required by the participant.

Ex.
- Total number of hours expected for preparation = 5
- Activity time = 3
- Post activity = 1
- Total = 9 hours

Indicate the type of activity the participant is being asked to take part in.

Ex. Travel is expected
- Local travel
  - Hours = 2
Patient Engagement Activities Framework (3/3)

- **Travel Considerations.**
  - Ex. A caregiver must accompany

- **Indicate here other potential modifiers that could have an impact on compensation or reimbursement.**
  - Ex. Childcare or eldercare needed

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.
National Health Council Fair-Market Value Calculator
National Health Council Patient Engagement Fair-Market Value Calculator

Please review the instructions before beginning.

Instructions for Use:

Please read the information below before using the FMV Calculator.

Before using the FMV Calculator, you should have already clearly defined the specific activity in which patients, caregivers or patient organizations will be engaged, type and scope of the activity, expertise required to perform the activity, type of participant, and number of hours required to perform the activity, as well as hours for any travel required.

Ready to begin?

Begin FMV Calculation!

I accept the Terms of Service

Copyright © 2020 National Health Council, All rights reserved.
National Health Council Patient Engagement Fair-Market Value Calculator

Please review the instructions before beginning.

To use:

Read the information below before using the FMV Calculator.

If you are using this calculator, you should have already clearly defined the specific activity in which or patient organizations will be engaged, type and scope of the activity, what will be performed, the activity, type of participant, and number of hours required to complete as well as hours for any travel required.

Ready to begin?

Begin FMV Calculation!

I accept the Terms of Service
Case Example
Scenario Example

• A company recruits a patient-group staff representative who is a senior leader at the organization to serve as a virtual roundtable participant about patient-focused drug development.

• The participant is requested to have subject matter expertise on a particular topic.

• The participant must read materials before the roundtable, which will take approximately 3 hours.

• The roundtable itself will take approximately 3 hours.

• The post-roundtable survey will take the participant approximately 1 hour.

Fair Market Hourly Rate: $150.00 to $350.00

Total Fair Market Value Compensation (Excluding Expenses): $1,050.00 to $2,450.00
NHC Fair-Market Value Calculator

Accompanying Resources

- User Guide
- Interpreting Results
- Methodology
- Glossary
Interpreting Results

Example issues you will want to consider in making choices within an FMV range include:

- Risk of liability (e.g., legal or financial) or stress from participating in engagement (e.g., member of a Data and Safety Monitoring Board).
- Wages lost (e.g., time off of work for hourly workers who might not otherwise participate and might impact the recruitment of a representative target population) and should be considered on a case-by-case basis,
- Urgency (e.g., a very short time to prepare, create something, or complete a deadline for an activity).
Interactive Session – FMV Calculator
Scenario Example Worksheet

FMV Calculator Worksheet

Instructions for Use: Please use this worksheet to help you complete the NHC Fair-Market Value Calculator. The Calculator uses the expertise level and the activity time information to calculate a fair-market value range. Other questions on this worksheet help you determine if there will be extra costs incurred due to special circumstances or other considerations.

Example: A company recruits a patient-group staff representative who is a senior leader at the organization to serve as a virtual roundtable participant about patient-focused drug development. The participant is requested to have subject matter expertise on a particular topic. The participant must read materials before the roundtable, which will take approximately 3 hours. The roundtable itself will take approximately 3 hours. The post-roundtable survey will take the participant approximately 1 hour.

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<tr>
<th>Participant Information:</th>
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<tbody>
<tr>
<td>Participant Type (Check one only)</td>
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<tr>
<td>- Individual Patient</td>
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<tr>
<td>- Caregiver</td>
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<td>- Family Member</td>
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<tr>
<td>- Patient Group Representative</td>
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<td>Other: ____________________</td>
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<tr>
<td>Patient Needs a Confirmed Diagnosis</td>
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<tr>
<td>Yes (or caring for someone that has a confirmed diagnosis)</td>
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<td>Diagnosis: ____________________</td>
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<tr>
<td>Patient Needs to Have Treatment Experience</td>
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<tr>
<td>Yes</td>
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<tr>
<td>Describe: ____________________</td>
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<td>If a Patient Group Representative, Must</td>
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Examples Submitted!

• We would now like to call on a few attendees to walk through example scenarios that were submitted in advance using the worksheet we sent earlier this week.

• We will switch to live use of the FMV calculator.

• If we have time, we’ll do a few more that others may have.
Use it on your own:

https://nationalhealthcouncil.org/patient-compensation-tools/
Feedback

• Please let us know what you think about the FMV calculator and accompanying materials.

• You can email NHCprograms@nhcouncil.org with any comments or questions.
Thank you!