

# 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

**PEOF2020 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)
- National Health Council Patient Engagement Fair-Market Value Calculator Toolbox (organised by NHC)

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 or/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 EFGCP)

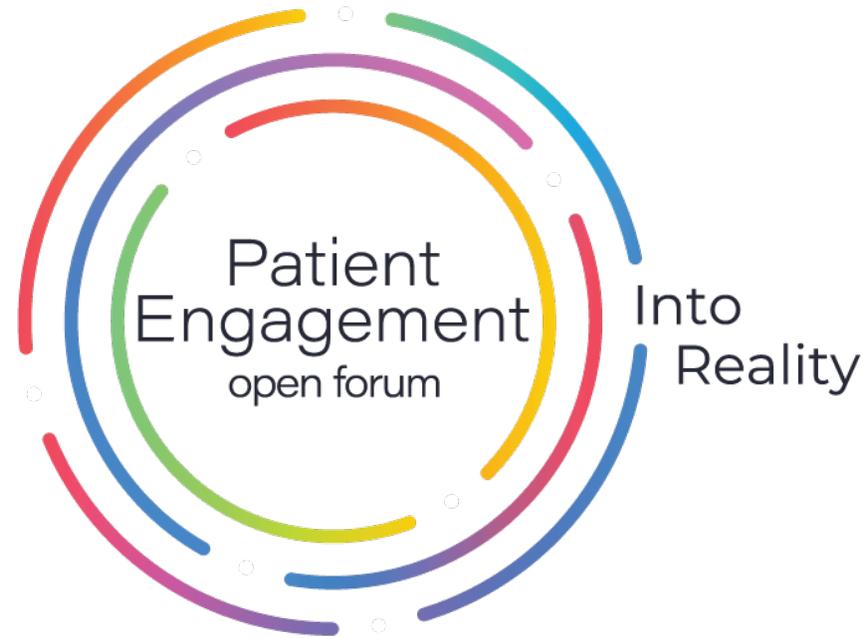
November 5th

**THEME: Regulatory**

November 23rd

**Plenary session:**

- PEOF2020 conclusion session



# National Health Council Patient Engagement Fair-Market Value Calculator Toolbox

Eleanor Perfetto, PhD, MS  
& Silke Schoch





Thank you!

# Sponsors

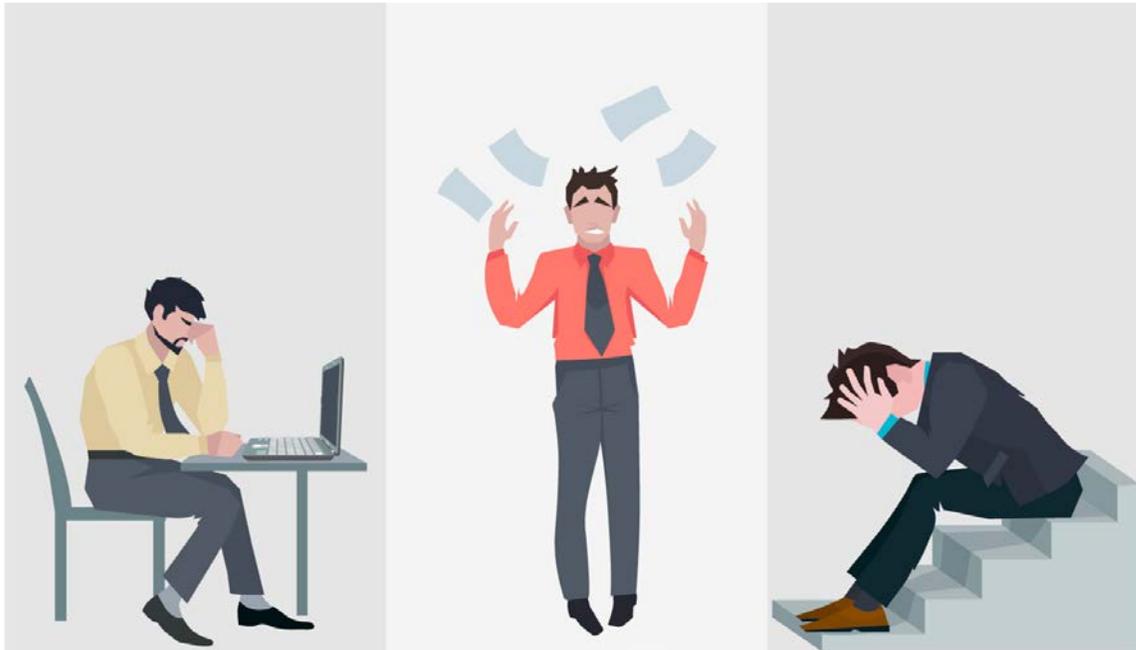
Johnson & Johnson	Platinum Premier
Merck & Co., Inc.	Platinum Premier
Novartis Pharmaceuticals Corporation	Platinum Premier
Patient Focused Medicines Development	Platinum Premier
Pfizer Inc.	Platinum Premier
Allergan	Premier
Biogen	Premier
Boehringer-Ingelheim Pharmaceuticals	Premier
Grifols	Premier
People-Centered Research Foundation	Premier
Sangamo Therapeutics	Premier
UCB, Inc.	Premier
Celgene Corporation	Leading
Servier Pharmaceuticals	Leading

# 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

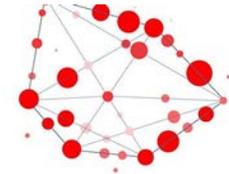
---

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

- Representation on the Steering Committee
- Adapt deliverables



PATIENT FOCUSED  
MEDICINES DEVELOPMENT



**WECAN**



NATIONAL  
HEALTH COUNCIL

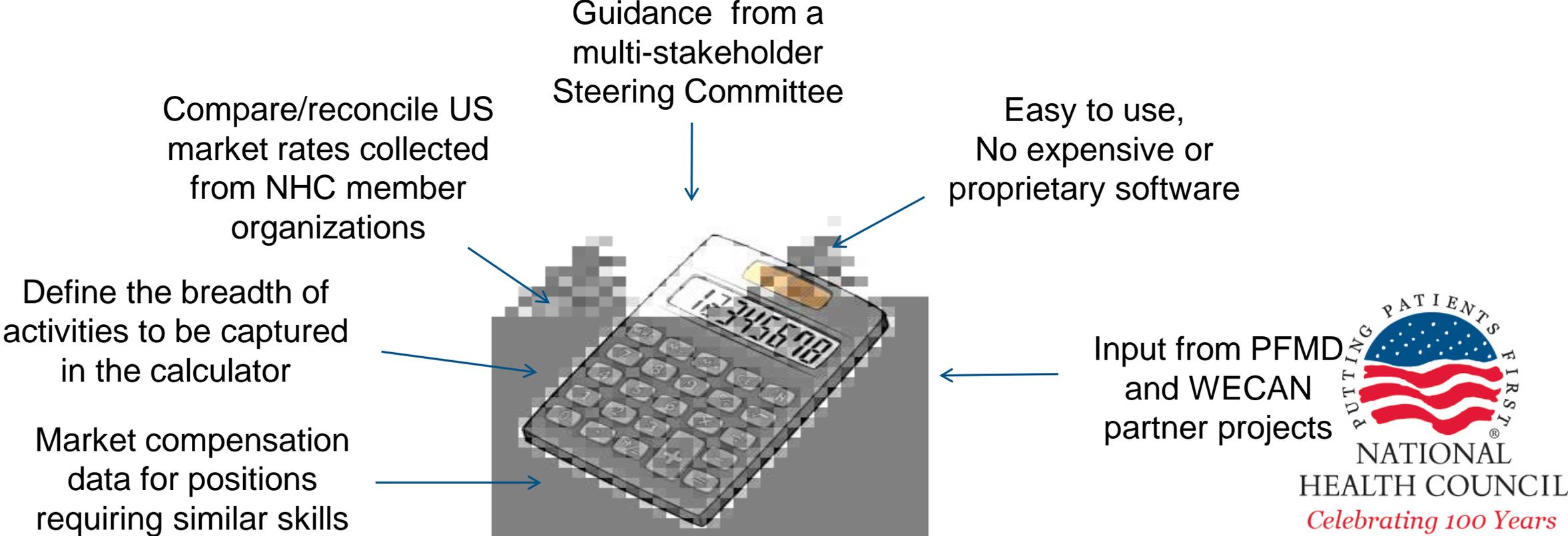
*Celebrating 100 Years*

# Methods

---

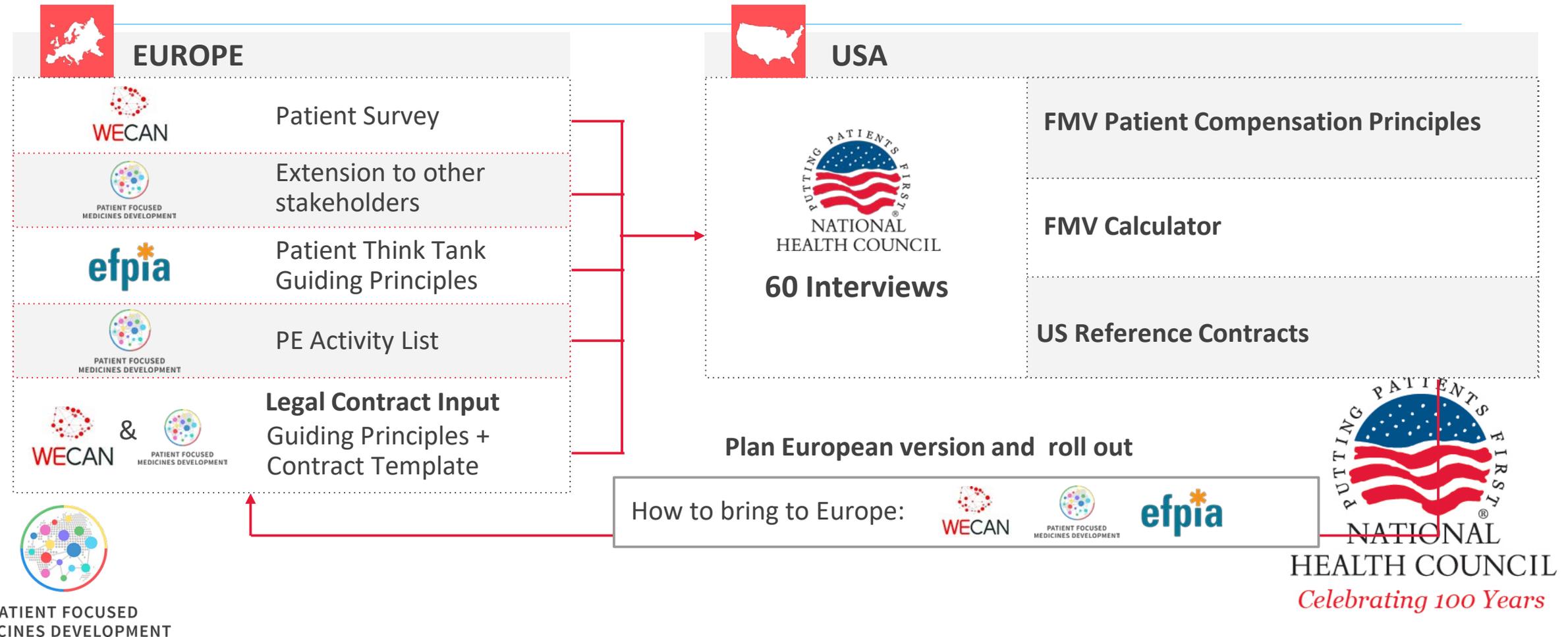


# Developing the FMV Calculator



# Getting FMV Right

## FMV Input



# 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
  - Research Positions
  - Marketing 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



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

Ex. Knowledge about the condition beyond individual/personal experience



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

## Ex. Presentation/speaker

- Keynote

# 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)



# 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](#)

Home

Anti-trust Statement

User Guide

Interpreting FMV Results

Glossary of Terms

FMV Hourly Rate Methodology

Terms of Service

Last Report Summary

# National Health Council Patient Engagement Fair-Market Value Calculator

Please review the instructions before beginning.

Use:

on below **before** using the FMV Calculator.

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

**Ready to begin?**

Begin FMV Calculation!

I accept the [Terms of Service](#)

# NHC Fair-Market Value Calculator Accompanying Resources

---



**User Guide**



**Interpreting Results**



**Methodology**



**Glossary**



# 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).

Fair Market Hourly Rate:  
\$150.00 to \$350.00

Total Fair Market Value Compensation (Excluding Expenses):

\$1,050.00  
to  
\$2,450.00



# 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**.

### Participant Information:

Participant Type (Check one only)	<input checked="" type="checkbox"/> Individual Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Family Member <input type="checkbox"/> Patient Group Representative Other _____
Patient Needs a Confirmed Diagnosis	Yes (or caring for someone that has a confirmed diagnosis) Diagnosis _____
Patient Needs to Have Treatment Experience	Yes Describe: _____
If a Patient Group Representative, Must	_____



NATIONAL  
HEALTH COUNCIL  
*Celebrating 100 Years*

# 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](mailto:NHCprograms@nhcouncil.org) with any comments or questions.



# Thank you!

