

**WECCAN**

Workgroup of European  
Cancer Patient Advocacy Networks

# **Compensation for patient experts at fair market value**

**WECCAN Workgroup on FMV:  
Jan Geissler, Ananda Plate, Gilliosa Spurrier,  
Judith Taylor, Kathy Oliver, Gordon Oliver**

Jan Geissler, 28 Oct 2018

# **Rationale of the WECAN project on Fair Market Value**

# Why is „fair market value“ an issue?

- Patient advocates...
  - are mission-driven, but some individuals need to make their living – it should be their own choice to volunteer or not
  - that are staff members still need to have (and pay for) more staff if contributing to an increasing number of stakeholder meetings
  - are often the only unpaid/poorly paid experts in the room
- Financial compensation for patients should be offered at meetings of industry/regulators/other stakeholders for...
  - advisory and collaborative roles (“patient input”)
  - consultancy work (e.g. support the creation of services)
  - speaker roles at internal meetings
  - speaker roles at external events and conferences
- Financial compensation should be considered not only by industry, but also by governmental committees or commercial conference organizers

# What are the unresolved challenges in applying fair market value of patient advocates?

- Industry nervous about perception of **bribery**
- Patient experience and expertise not valued **in the same way as other professionals**
- Frequently even **no compensation offered** (“networking” seen as “return on invest”)
- **Rarely FMV differentiation** between patients with individual disease experience vs. highly trained, experienced patient experts
- **Preparation time** for meetings often disregarded
- **Inconsistency** of FMV methodologies across companies (in rates, engagement time, travel time)
- **Huge variance in rates**: Often the least common denominator
- **No choice about recipient** (to individual or to organisation)
- **No right to refuse compensation** (opt out)

# Fair, systematic and structured approach to fair market value is needed

- **Both patient organisations and industry see the need for a fair, systematic and structured approach to compensation to patients, representing fair market value**
- Evaluation of fair market value could be done e.g. on
  - **individual experience/expertise** (e.g. years of experience, prior training, involvement in scientific meetings, transferable skills)
  - **level of contribution**
  - **complexity of tasks** delivered (pure participation, small tasks, trainer/reporter, specialist/expert level)
  - **total time invested** (preparation, presence and follow-up time, travel time)

# What we can draw on...

- EUPATI Guidance's definition of patients
  - **“Individual patients” / “carers”**: personal experience of living with disease
  - **“Patient Advocates”**: insight & experience in larger population of patients
  - **“Patient Organisation Representatives”**: expressing the collective views of a patient organisation
  - **“Patient Experts”**: in addition to disease-specific expertise, have the technical knowledge in R&D and/or regulatory affairs
- EATG's tool which grades compensation in accordance with complexity of tasks – this formula works
  - 1 – work group participation
  - 2 – small tasks- e.g protocol revisions
  - 3 – intermediate level, e.g. trainer, report work
  - 4 – specialist/expert level
- Change Foundation's Decision Tool

**Current status of  
WECAN project and  
results of WECAN FMV survey**

# Current status of WECAN project on FMV

- ✓ Finalisation of WECAN Reasonable Legal Agreements „Guiding Principles“, provides consensus baseline for WECAN FMV project (see [www.wecanadvocate.org/rapp](http://www.wecanadvocate.org/rapp))
- ✓ Survey of patient advocates on expectations on FMV (July-September 2018)
- Publication of WECAN survey results, developing WECAN position paper, refining criteria on e.g. measuring individual expertise and training
- Liaison with external stakeholders working on FMV (e.g. EFPIA). WECAN representative: Susanna Di Leto <susanna.letto@fastwebnet.it>
- Provide input into development of scoring systems based on factors (individual expertise and training, complexity of tasks, total time invested, country of origin / regional differentiation, other contributing factors). Work with PFMD.

## Guiding Principles

- Compensate according to fair market value, **taking into account e.g. individual expertise and training, total amount of time invested, complexity of tasks, country of origin**, similar to other highly trained professionals
- **Reflect total time invested**, incl. physical presence and preparatory time. Consider also part of travel time.
- Respect the **right to refuse compensation**
- **Cover reasonable travel expenses**
- **Long-distance flights** justify higher flight class
- **Reasonable 3-way travel costs on advocacy duty** should be covered
- **Multi-day stopover on advocacy duty** should be permitted
- **Pay within 30 days**

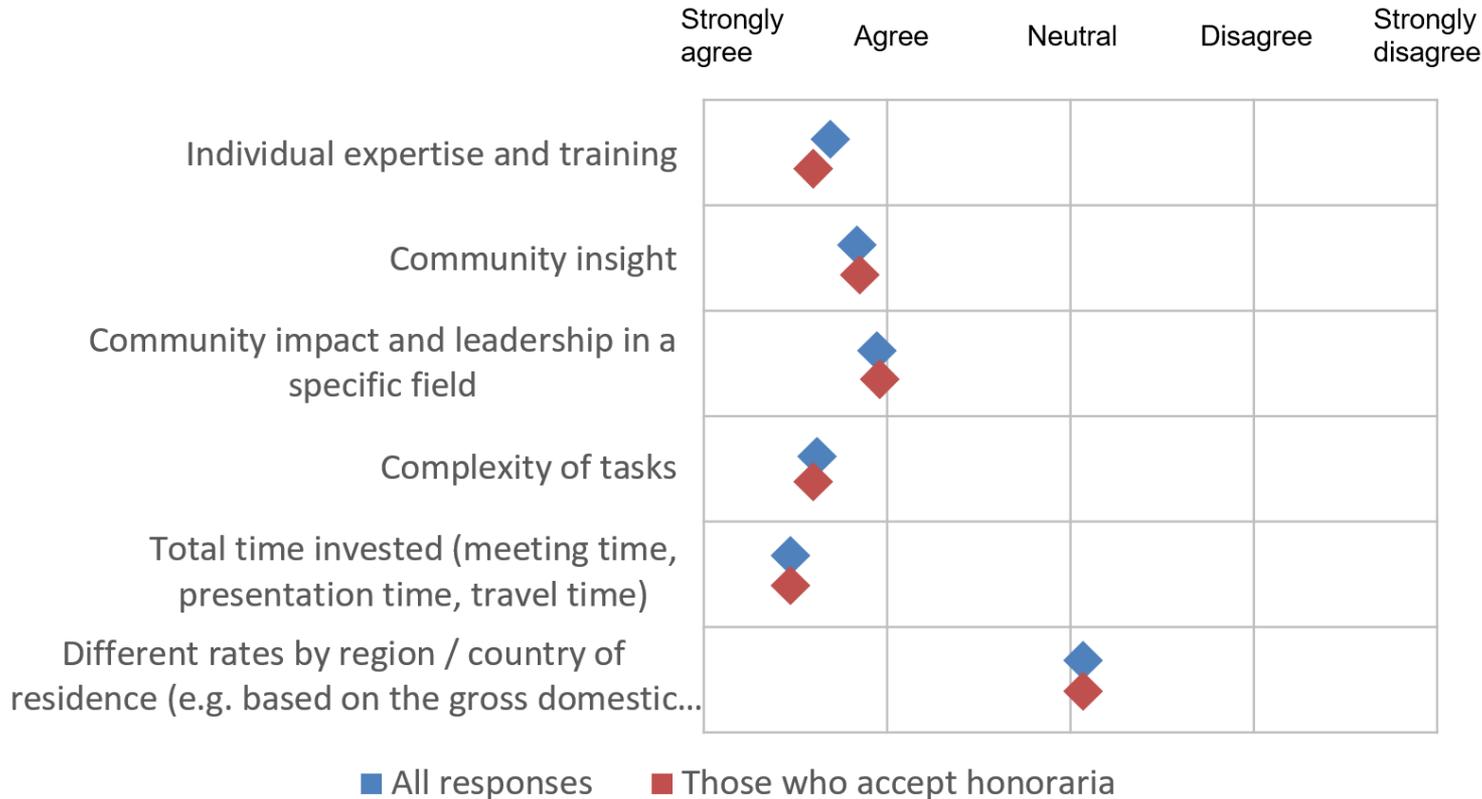
# WECAN Survey on FMV: Respondents

- **122 responses of patient advocates from 38 countries** received between 23 July-10 Sept 2018
  - 41.8% from solid cancers (n=51)
  - 15.6% from non-malignant and malignant hematology (n=19)
  - 9.8% from non-cancer rare diseases (n=12)
  - 20.5% from other disease areas (e.g. rheumatic, psoriasis, multiple sclerosis, Parkinson's, lung diseases like COPD and asthma, metabolic, infertility, HIV, bone diseases, n=25)
  - 12.3% without specific disease focus, or disease not mentioned
- **68.0% of respondents accept financial compensation** for their individual activities as patient advocate or expert, either personally or through their organization (n=83)
- **74.7% of those who generally accept compensation** also received financial compensation in the past 6 months

# Brief summary of WECAN FMV Survey

- **Patient community strongly agrees** that the individual expertise, community insight, community leadership, complexity of tasks, total time invested should **increase FMV value rate**
- **Factors for measuring individual expertise** should include specifically advocacy track record, disease and treatment knowledge, healthcare/research systems knowledge, personal skills, completion of training programmes, personal experience
- **Different rates by country of residence** were seen skeptical
- **Patient community disagrees** that factors like networking opportunities, travel, learning, prestige, visibility, access to treatments or HCPs should **decrease the FMV rate**
- **Travel time** should be compensated, either full or at least partial. Only 16% think no compensation for travel time is fair.
- **Right to opt out from financial compensation, and right of choice of recipient** (PAG or patient advocate) has strong support

# Factors that potentially increase FMV rate



Variance_all
0,89
0,82
1,14
0,72
0,61
1,51

Strong agreement on FMV differentiation based on individual expertise and training, community insight, community impact and leadership, complexity of tasks, total time invested.  
 Strong variance in opinion whether FMV rate should be influenced by country of residence of patient advocate. No significant difference in opinion between those that receive honoraria and those who don't.

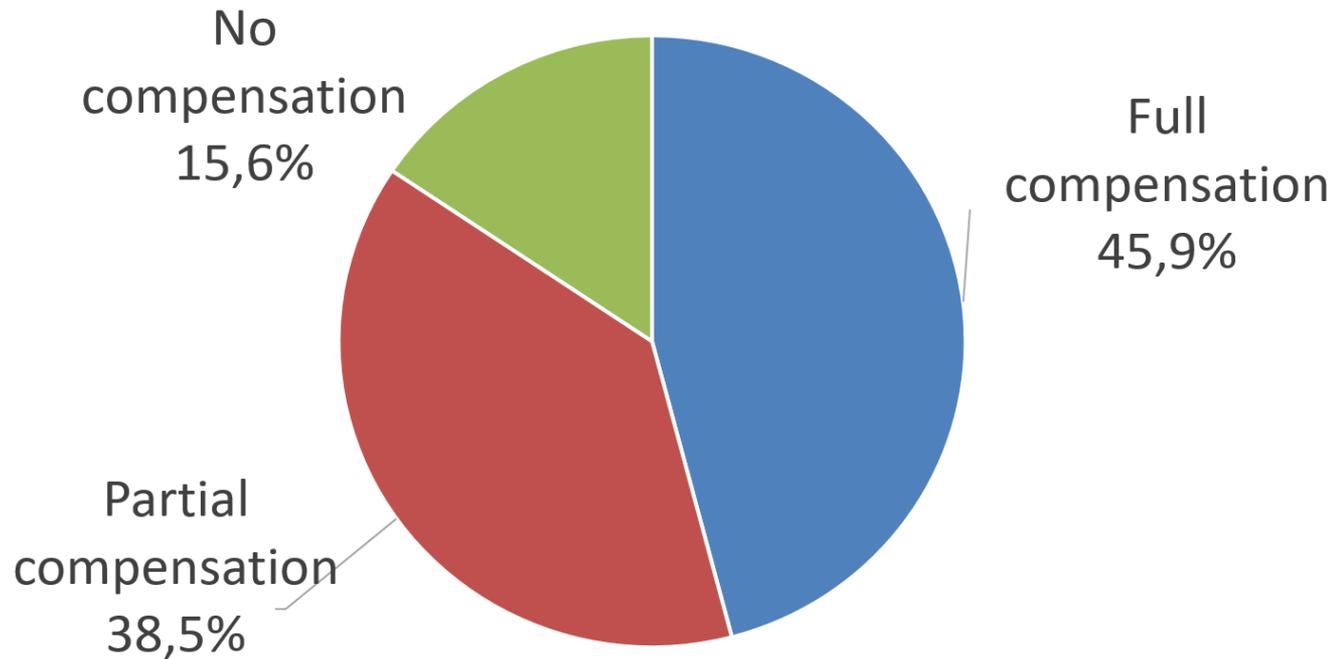
Q4: When looking at the Fair Market Value rate that patients and patient advocates receive as compensation for tasks (such as advisory boards, doing presentations, providing feedback, protocol review etc), should the following factors increase the level of your financial compensation: Rate 1-5: strongly agree, agree, neutral, disagree, strongly disagree: n=122 responses

# Qualitative responses on “factors increasing FMV rate”: Other contributing factors

## Other contributing factors:

- **Workload, not only complexity** (being the secretary of a CAB / workgroup / board may not be complex but a highly demanding one)
- **Contributor vs participant:** differentiate between someone who just turns up on the day and someone who engages with a community, goes on courses, reads relevant literature and formulates questions, has expertise in attending meetings, understanding how to talk to others etc. Paying 'grassroots' the same as 'experts' is not on, and devalues involvement.
- **Rarity of task**
- **Certifications** that prove specific competences, e.g. EUPATI training absolved, but also others
- **Formal education, business experience**
- **Involvement in EU / EMA / healthcare provider**
- **Involvement in Guidelines** (local, European or global)
- **Background of the patient advocate like:**
  - Level 1: Peer communication
  - Level 2: Patient support and disease education,
  - Level 3: Disease awareness & early recognition in general public
  - Level 4: Communication with Providers
  - Level 5: Improve therapeutic options(availability, access)
  - Level 6: Improve policies & HC priorities
  - Level 7: Improve outcomes

# Compensation for travel time



84.4% of patient advocates feel that it would be most fair to receive full compensation or at least partial compensation of travel time. Only 15.6% feel it is fair not to compensate travel time at all.

# Qualitative responses on “compensation for travel time”

## Use of travel time vs. “lost time”:

- Very often we spend more time on travel than on a meeting, and with our regular jobs, we lose half a day on that activities and the organizers, in many cases, don't value that.
- If, during travel, the time can be spent working on matters for other parties then that time and the compensation for it should be discounted. Proper accounting for time of travel on that basis is the fairest way forward.
- It happens that the meeting takes an hour or 2 and you have to travel most of the day to get there and get back...
- We also must consider the time spent for preparing the meeting: TC, skype calls, emails, articles review, Power Points presentations, etc. I said "Partial compensation" because I use my travelling times to work for my organisation.

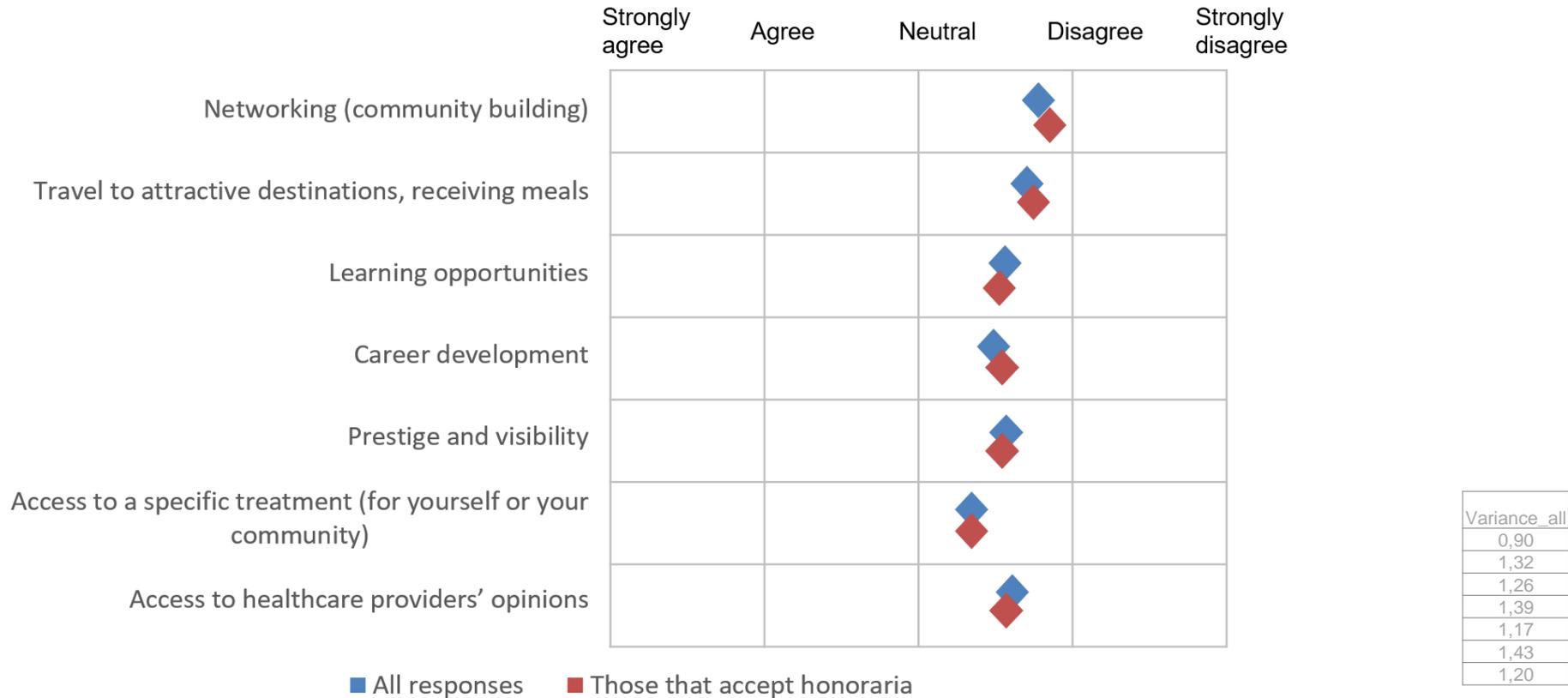
## Opportunity cost of travel time (in terms of health and money):

- Patient advocates with young children need to hire a baby sitter to be able to travel meaning that this cost should be covered.
- Travel is not just about lost time. For people with diseases, it is about lost time AND potentially increased fatigue/pain/disease symptoms, before/during/after the event.
- It is impossible to fundraise, especially from pharma, to cover all travel costs, not to mention daily allowance.

## Rates for travel time:

- What about a travel rate rather than the rate paid for attending the meeting
- A 'day rate' based on time away from the office similar to the way that professional consultants are compensated.
- If travel is not compensated then the value of actual time spent in meetings should receive greater reimbursement to compensate for the hours in travel. A fix time could be considered for European travel for all, say 4 hours.
- If the advocate is part of an organization the fairest fee is 50% of the cost. But if you are working as an individual full compensation would be more adequate.

# Factors that potentially decrease the FMV rate



Patient advocates disagree that networking opportunities, nice locations of meetings, learning opportunities, career development opportunities, prestige and visibility or access to healthcare providers justify a reduction of FMV rates. Improving access to specific treatment for themselves or their community had lowest level of disagreement.

# Qualitative responses on “factors decreasing FMV rate” – additional factors and comments

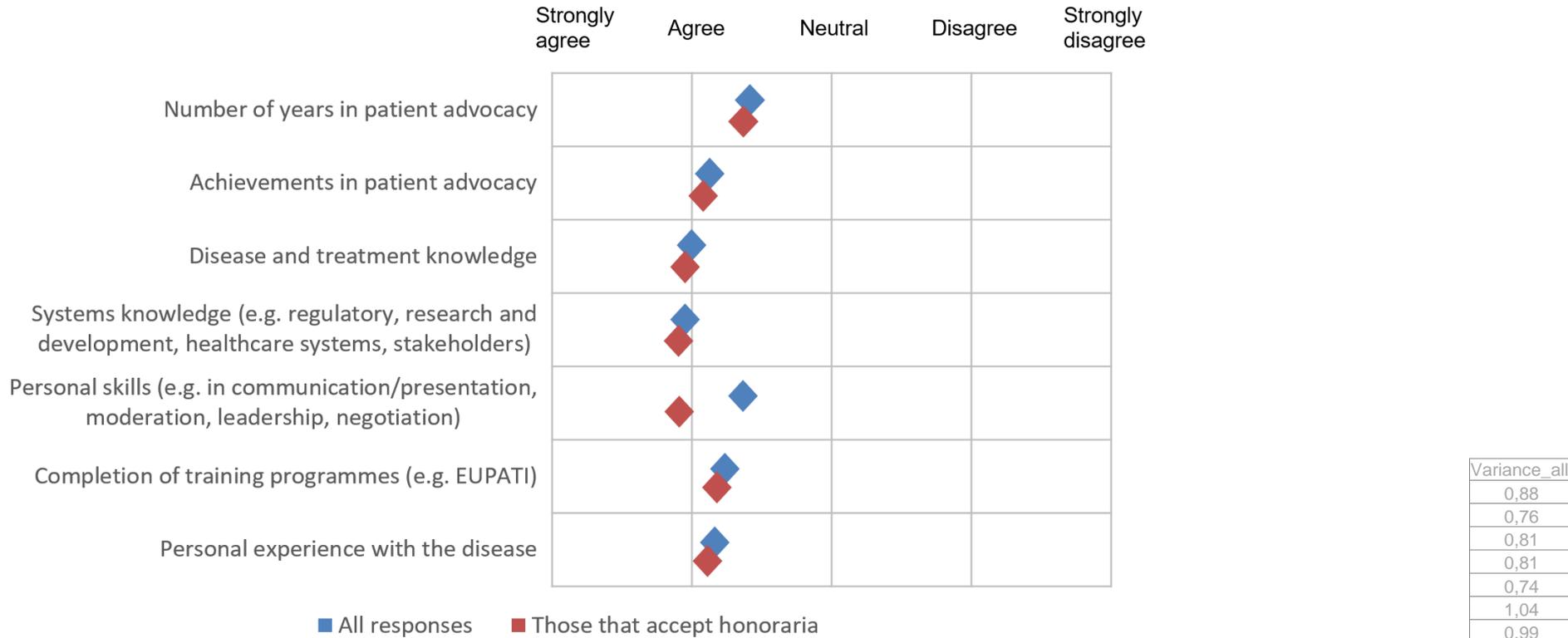
## Additional factors decreasing FMV rate:

- Being a "quiet member" without added value but just a representative (which is not ideal).
- Making a difference. Altruism.
- Office patient or real patient. Too many people out there speaking on what patients want and what not, without ever having surveyed their community to harvest what important issues from them.

## Additional comments:

- Like in other professions, **if you have expertise you should be paid more, not less.**
- **Decrease on any of the factors would provide perverse incentives.** The most financially rewarding events would be the least useful. Making less attractive events (the ones we don't want to go to) pay more and the useful ones pay less.
- **Ask yourself the same questions but using a statistician** as an example instead of a patient. Would you expect to pay them less if they had biscuits with their coffee at meetings? Would you expect to organise a room for them and pay for that if the meeting was in a different country? Would you expect them to pay you because attending your meeting MIGHT enhance their status a little? NO? Why here? Quibbling over whether you pay them using shopping vouchers, or even whether they should be paid because it might 'compromise their neutrality' is insulting.
- "Access to Treatment" and "to healthcare providers' opinions": If you are seeking the access for yourself or for your community → **for yourself personally should be a decreasing factor, for your community not.**
- **Too much subject to interpretation.** A pharma company might "believe" they are offering career development or a learning opportunity, e.g., "to learn about trials"... but they are not. They might think they are giving us access to healthcare providers' opinions, but we have that anyway. Unacceptable.
- **Risk of exploiting the most vulnerable people in the process.** It's patients' feedback and contributions that make most pieces of work credible. We cannot survive on 'prestige & visibility', 'healthcare worker's opinions' or 'going to nice places'. Although may facilitate career development (therefore higher income earnings), it's not guaranteed, the outcome is harder to measure and who's to say when that would happen.
- **Compensation should not be based on what a patient advocate can get out of it,** but what he/she can contribute
- “Advantages” like networking or learning opportunities are **included in any sort of human relations or meeting.**
- Generally an organization should always be **compensated for a worker being elsewhere**

# Factors for measuring individual expertise and training



In order of priority, patient advocates agree that factors like systems knowledge, disease knowledge, achievements / track record in advocacy, personal experience with disease, completion of training programmes and number of years in patient advocacy could be used to measure individual expertise. There was a difference between those that receive honoraria and those who don't whether personal skills should influence the FMV rate.

# Qualitative responses on “measuring individual expertise and training”: Any other factors?

## Relevance to task to be delivered:

- It's really difficult completing this exercise because it depends a lot on the initiative we are talking about. Each factor directly depends on the objective and purpose of the initiative.

## Equality with other HCPs:

- The real question is "how much are we worth?" and it's very simple - the same as all other stakeholders. If clinicians get X per day, well, so should patients (or patient experts, if we want to call them that).

## How to measure individual expertise and training:

- What's the methodology to assess knowledge? a number of factors such education, professional experience, personal skills, foreign languages, thorough knowledge of the disease
- Knowledge is key to good advocacy and this is why I've scored those that might better measure that higher. Personal experience is usually a strong enough motivator to ensure good knowledge.

## Additional factors to consider on expertise and training

- Communication skills (this was embedded in personal skills), but it is worthy of a category on its own. Without excellent communication skills (in the target language), the advocate has a limited role. How about "Unique subject matter expertise, publications, specialisation" -- e.g., for advocates who have truly unique/outstanding subject matter expertise to bring to a specific topic/ discussion
- What about the language skills of the person, given the language they are expected to present in or participate in? I get the impression that mother-tongue or fluent speakers are preferred to second-language speakers.
- Analytical thinking.
- Being able to surpass the individual disease experience and look with a broader perspective.
- Expertise in other areas

# Other issues to be considered when agreeing on financial compensation for tasks

- 63.9% agree that the **“Right to opt out from any financial compensation (e.g. if codes of practice or bylaws of the organisation does not allow any compensation)”** should be considered’
- 87.7% think that the **“Right of choice of recipient of payment (to the organisation, or to the patient advocate, or donation to a third party etc)”** should be considered

# Next steps of WECAN project on FMV

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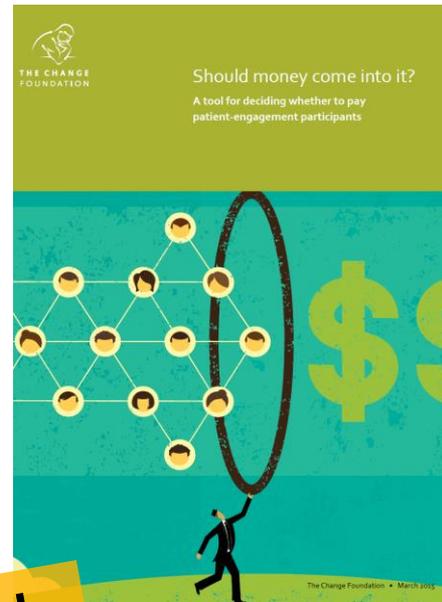
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**Backup slides**

# Change Foundation's Decision Tool: Scoring System for Compensation

- Canadian „Change Foundation“ proposed a decision tool for payment/non-payment decisions based on 8 factors
- Contributing factors / positive scores
  - Time invested (<8h...40h/month)
  - Equity – paid individuals
  - Engaging with people from vulnerable populations
  - Risk of embarrassment, psychological discomfort
  - Maintaining commitment (<12 months)
- Mitigating factors / negative scores
  - Positive impact of participant's life (community building, travel or learning opportunities, prestige, satisfaction)
  - Does it give access to treatment, HCP opinion
  - Forms of recognition (thank-you cards, meals, souvenir clothing, trips, scholarships)

**Change Foundation's conclusions and decision tool largely rejected by European patient community, especially mitigating factors**



Score 0-8:  
Payment not required

Score 8-12:  
Payment advisable  
but not required

Score 12-25:  
Payment required on  
top of other forms of  
recognition

Source: [www.changefoundation.com](http://www.changefoundation.com) (2015),

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# Change Foundation's Decision Tool

CONTRIBUTING FACTORS	SCALE	SCORE
<b>TIME</b>		
This looks at how much time participants will be asked to contribute (in duration and intensity both). NOTE: If you receive the "Automatic YES," that means payment is required and you need not complete the tool.		
<input type="checkbox"/> UNDER 8 hours / month	0	
<input type="checkbox"/> 8 – 16 hours / month for less than 3 months	1 POINT	
<input type="checkbox"/> 8 – 16 hours / month for more than 3 months	2 POINTS	
<input type="checkbox"/> 17 – 40 hours /month for less more than 3 months	4 POINTS	
<input type="checkbox"/> 17 – 40 hours /month for more than 3 months	5 POINTS	
<input type="checkbox"/> OVER 40 hours / month	Automatic YES	
<b>EQUITY</b>		
The question here is whether participants will work alongside people (e.g., healthcare workers, academics, policy makers) whose employers are paying them to be there. For scoring purposes, this does not include staff of The Change Foundation, who are assumed to be present at all or most engagement events.		
<input type="checkbox"/> No paid individuals at the table	0	
<input type="checkbox"/> Paid individuals at the table	5 POINTS	
<b>VULNERABLE-POPULATION STATUS</b>		
This scores the degree to which participants will be sought from "vulnerable groups," even those who have chronic physical conditions, mental health problems or addictions; are recent immigrants; are of color; are to racial or ethnic minorities; are Aboriginal; have low socio-economic status; are homeless, etc.		
<input type="checkbox"/> Not looking to engage vulnerable populations	0	
<input type="checkbox"/> Expect to engage some people from vulnerable populations	3 POINTS	
<input type="checkbox"/> Will mainly or exclusively engaging people from vulnerable populations	5 POINTS	
<b>CHALLENGES</b>		
This scores the likelihood of challenges for participants (e.g., risk of embarrassment, psychological discomfort) OR for the Foundation (e.g., hard cultural- or geographic-representations, history of similar failed projects, or timeline that may dissuade participants). The emphasis is on pragmatic: using payment to help attract and retain people when it may otherwise be hard to do so. However: NOTE that, regardless of payment, project design should aim to minimize any discomfort for participants.		
<input type="checkbox"/> 0 – 1 challenges foreseen / and/or challenges should be easily dealt with	0	
<input type="checkbox"/> A few challenges identified (2 – 3 challenges)	3 POINTS	
<input type="checkbox"/> Several challenges present (4+ challenges)	5 POINTS	
<b>ACCOUNTABILITY</b>		
This is pragmatic again: the less "personal" the medium, the more likely that payment is advisable to strengthen participants' commitment/accountability. This also considers the challenge of maintaining commitment/accountability in projects that exceed certain timeframes.		
<input type="checkbox"/> Less than 12 Month commitment – any engagement methods	0	
<input type="checkbox"/> 12 – 24 Month commitment - some or all in-person engagements	1 POINTS	
<input type="checkbox"/> 12 – 24 Month commitment – virtual/remote engagements only (online, phone, etc.)	2 POINTS	
<input type="checkbox"/> More than 24-month commitment - some or all in-person engagements	4 POINTS	
<input type="checkbox"/> More than 24-month commitment – virtual/remote engagements only	5 POINTS	

MITIGATING FACTORS	SCALE	SCORE
<b>POSITIVE IMPACT</b>		
The more positive impact, the less likelihood of need for financial compensation. This can mean impact on the participant's life (e.g., community-building, travel or learning opportunities) and/or on the healthcare system (bringing prestige or satisfaction for participants).		
<input type="checkbox"/> Low or negligible positive impact expected (personal or system)	0	
<input type="checkbox"/> Medium positive impact (personal or system)	- 3 POINTS	
<input type="checkbox"/> High positive impact (personal or system)	- 5 POINTS	
<b>ACCESS</b>		
If the engagement gives participants access to specific treatments, healthcare providers' opinions, etc., this can also mitigate against payment.		
<input type="checkbox"/> No – no access to treatments or healthcare providers' opinions is anticipated	0	
<input type="checkbox"/> Yes – access to treatments or healthcare providers' opinions is anticipated	-5 POINTS	
<b>FORMS OF RECOGNITION</b>		
This can mean any form of recognition options (thank-you cards, meals, etc.), medium- to high-recognition options (trips, scholarships, etc.).		
<input type="checkbox"/> No – no other forms of recognition are planned	0	
<input type="checkbox"/> Yes – other forms of recognition are planned	-5 POINTS	
<b>CONTRIBUTING AND MITIGATING FACTORS</b>		<b>FINAL SCORE</b> (if negative enter "0")
<input type="checkbox"/> All categories have been scored		

**Change Foundation's conclusions and decision tool largely rejected by European patient community, especially mitigating factors**

COMPENSATION DECISION AND NOTES	SCORE RANGE
<b>Payment not required:</b> Other options to recognize participant contributions are advisable.	0 to 8
<b>Payment advisable but not required:</b> If you prefer not to pay, consider strengthening your mitigating factors or making other changes.	9 to 12
<b>Payment required:</b> This is in addition to any other forms of recognition that may be in place.	13 to 25