



PATIENT COMMANDO

Empowering patient choice

- Zal Press

DISCLOSURE

I have the following relevant financial relationships to disclose:

- Received honoraria from various pharmaceutical companies, academic institutions, research organizations, care delivery organizations, and government agencies across the continuum of care
- I do not make a living from these activities.
- CADTH provided travel award to present at today's Symposium
- I have been prescribed and purchased drugs from over a dozen manufacturers that have an aggregate value in excess of \$800,000

I have the following relevant non-financial relationship to disclose:

- I was founding Co-Chair of The Beryl Institute Global Patient and Family Advisory Council, a sister organization to the Patient Experience Journal which published our paper on today's topic.



Paying Patients

“Are you kidding?”

- Name withheld

A Patient Perspective on Compensation



"Experience is a hard teacher because she gives the test first, the lesson afterwards."

- Vernon Law



Do you have a
PhD in Lived Experience?

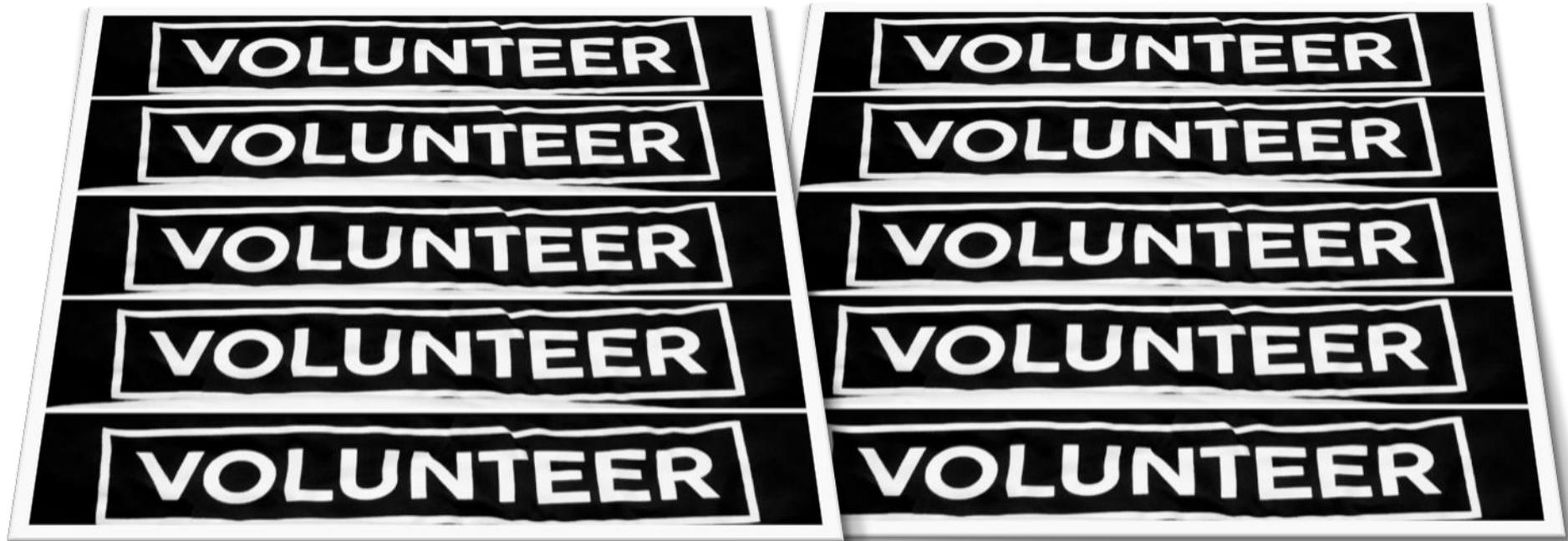


“People with chronic conditions are now explicitly conceptualized as part of the healthcare workforce, are delegated tasks by the system, and given performance targets. This can create new inequalities.”

- Carl May



Context



Is compensation a question of:

- value?
- equality?
- reciprocity?



Basic Principles

1. Removing barriers to participation

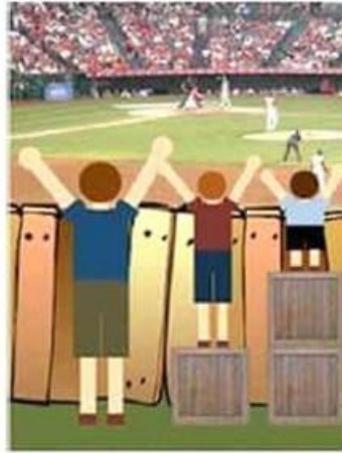


Basic Principles

2. Equity



In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.



In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.



In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

Basic Principles

3. Different Motivations



Basic Principles

4. Respect for vulnerability



Basic Principles

5. Commitment



Basic Principles

1. Removing barriers
2. Equity
3. Different Motivations
4. Respect for vulnerability
5. Commitment

What would you add?



Context

Compensation \neq payment of expenses

Expenses	Compensation
Out of pocket costs	Recognizes time, skills, energy
Eg. Mileage, transit, parking	Eg. Monetary, non-monetary

The Golden Rule

Start the Conversation



Start Early

- Addressed by project lead
- 1:1 conversation



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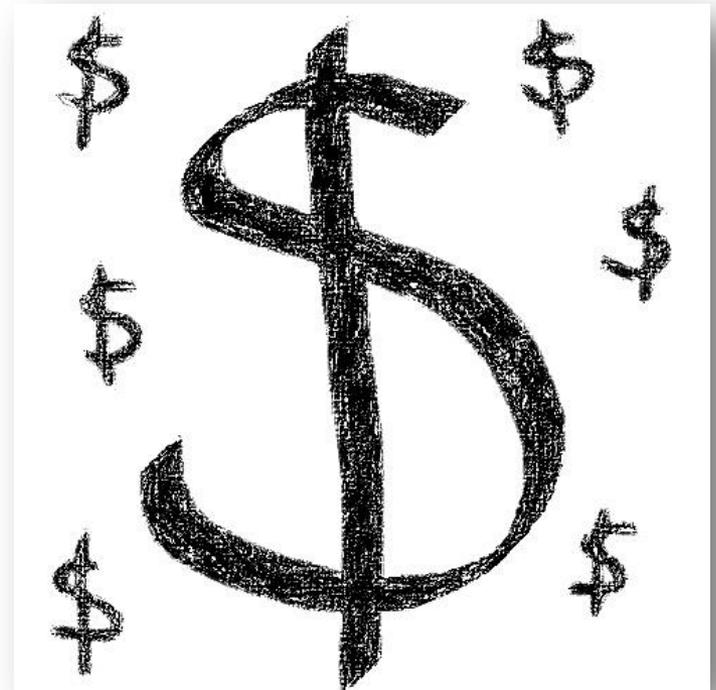
Rates

- Limited guidance
- Hourly, lump sum?
- Ask patients about own rates

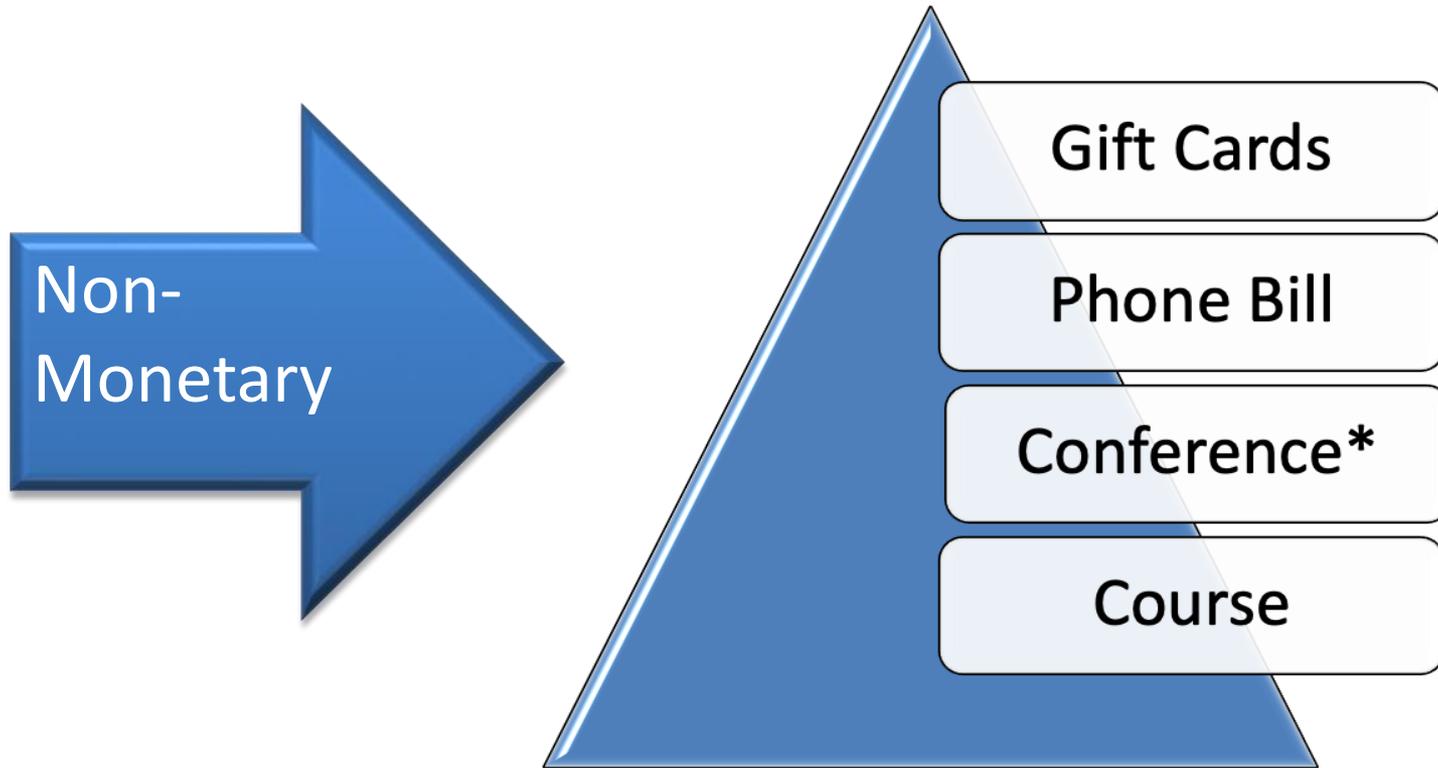


Implications of Monetary Compensation

- Taxes
- Disability payments



Non-Monetary Compensation



*Unrelated to the project

The How



“Sit them down and **ask them** how they want to be engaged....Don’t assume, just **ask!**”

Source: Black, A., et al., *What constitutes meaningful engagement for patients and families as partners on research teams?* Journal of Health Services Research & Policy, 2018.

BUDGET



Compensation
for
Patient Partners

Questions



Share with your neighbour:

- Questions you have now
- Questions you brought with you





Richards, Dawn P.; Jordan, Isabel; Strain, Kimberly; and Press, Zal (2018) "Patient partner compensation in research and health care: the patient perspective on why and how," *Patient Experience Journal*: Vol. 5 : Iss. 3 , Article 2.

Available at:

<https://pxjournal.org/journal/vol5/iss3/2>



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<http://bit.ly/PatientCompensation>

