



# Whose Voice?

When what matters to patients drives care

Isabel Jordan @seastarbatita





Who am I?



# Our Medical Mystery Tour







10 PM	117	66	114	118	66	84	95	55	98	106
15 PM	145	69	96	102	57	81	101	63	102	111
15 PM	82	58	97	133	70	85	93	50	109	108
14 PM	130	66	114	128	70	94	99	66	116	118
17 PM	106	79	112	114	50	100	114	66	104	102
11 PM	116	55	102	97	50	83	87	63	123	106
10 PM	116	77	108	109	55	81	88	54	110	105
10 PM	138	80	117	124	67	79	83	66	117	122
15 PM	127	79	112	110	67	96	95	72	122	131
10 AM	82	40	126	117	66	99	123	71	109	126
10 PM	134	66	104	114	62	92	127	56	106	129
10 PM	121	78	113	108	61	93	108	62	126	113
15 PM	117	81	116	137	81	90	103	66	117	122

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<input type="checkbox"/>	COLL/EXAM DATE ▼	SECTION	REPORTED BY	STATUS	OUT OF
<input type="checkbox"/>	2018-09-29 11:47	<a href="#">Haematology</a>	VPP	FINAL RESULTS	
<input type="checkbox"/>	2018-09-18 11:55	<a href="#">Haematology, Chemistry, Referred Tests</a>	CW	PARTIAL RESULTS	
<input type="checkbox"/>	2018-09-12 13:08	<a href="#">Haematology</a>	VPP	FINAL RESULTS	
<input type="checkbox"/>	2018-08-30 09:05	Transcribed Documents	TRANSPHS	FINAL RESULTS	
<input type="checkbox"/>	2018-08-28 08:45	<a href="#">Haematology, Chemistry</a>	CW	FINAL RESULTS	
<input type="checkbox"/>	2018-08-14 15:43	<a href="#">Haematology</a>	VPP	FINAL RESULTS	
<input type="checkbox"/>	2018-07-19 11:34	Transcribed Documents	TRANSPHS	FINAL RESULTS	
<input type="checkbox"/>	2018-05-25 16:17	Transcribed Documents	TRANSPHS	FINAL RESULTS	
<input type="checkbox"/>	2017-10-25 11:43	Transcribed Documents	TRANSPHS	FINAL RESULTS	

Emily M. Garland<sup>1,2,5</sup> · Jorge E. Celedonio<sup>1,2,6</sup> · Satish R. Raj<sup>1,2,3,4</sup>

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**Abstract** Postural tachycardia syndrome (POTS) is a form of chronic orthostatic intolerance for which the hallmark physiological trait is an excessive increase in heart rate with assumption of upright posture. The orthostatic tachycardia occurs in the absence of orthostatic hypotension and is associated with a >6-month history of symptoms that are relieved by

sympathetic tone, mast cell activation, decon

autoantibodies. Not only may patients be affo

than one of these pathophysiologies but also t

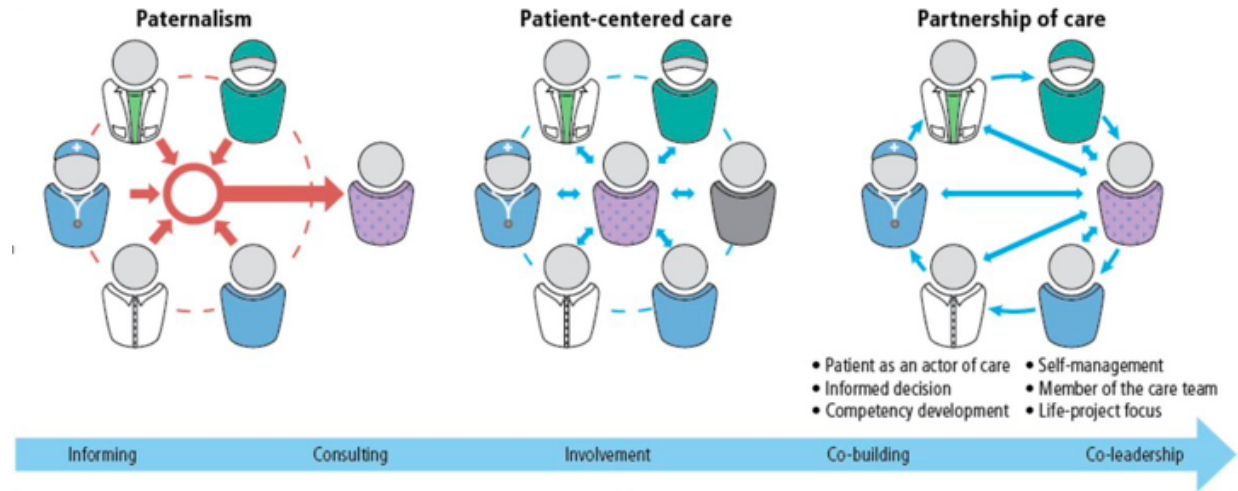
of POTS has similarities to a number of other d

chronic fatigue syndrome, Ehlers-Danlos syndr

gal syncope, and inappropriate sinus tachycar

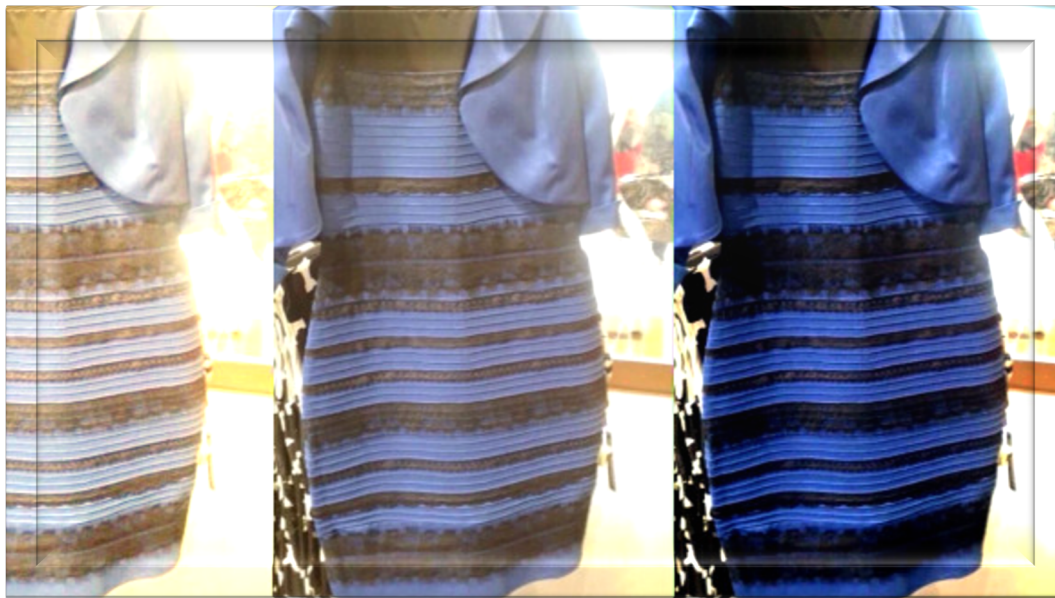


Who am I to  
you?



Pomey M, Lebel P.  
HealthcarePapers,  
16(2) October 2016:80-85

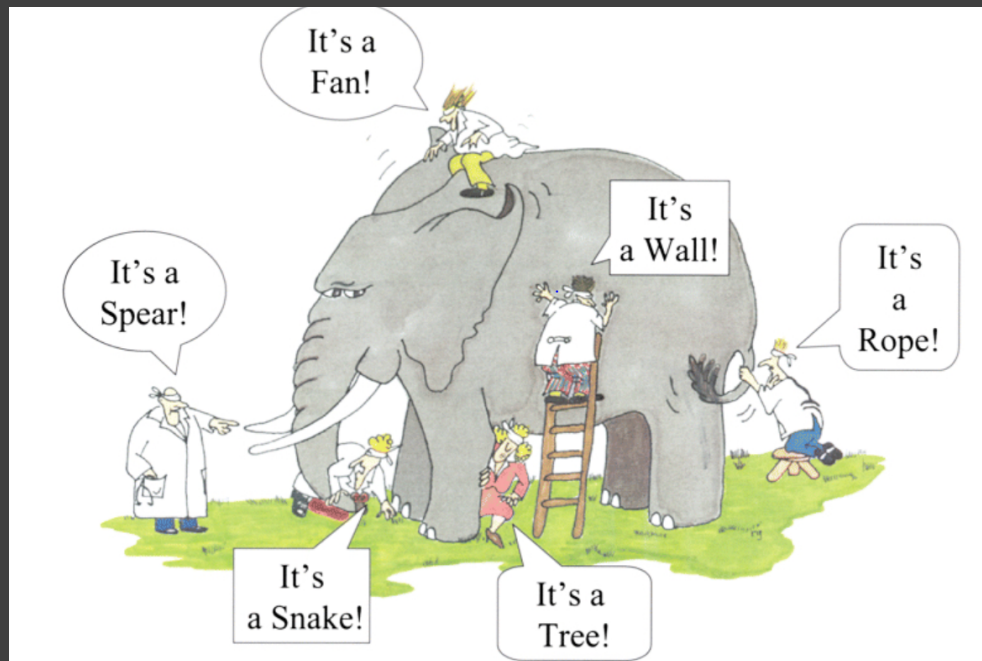




## The Internet Dress of 2015



# Why Partner with Patients?



- Perspective is Everything







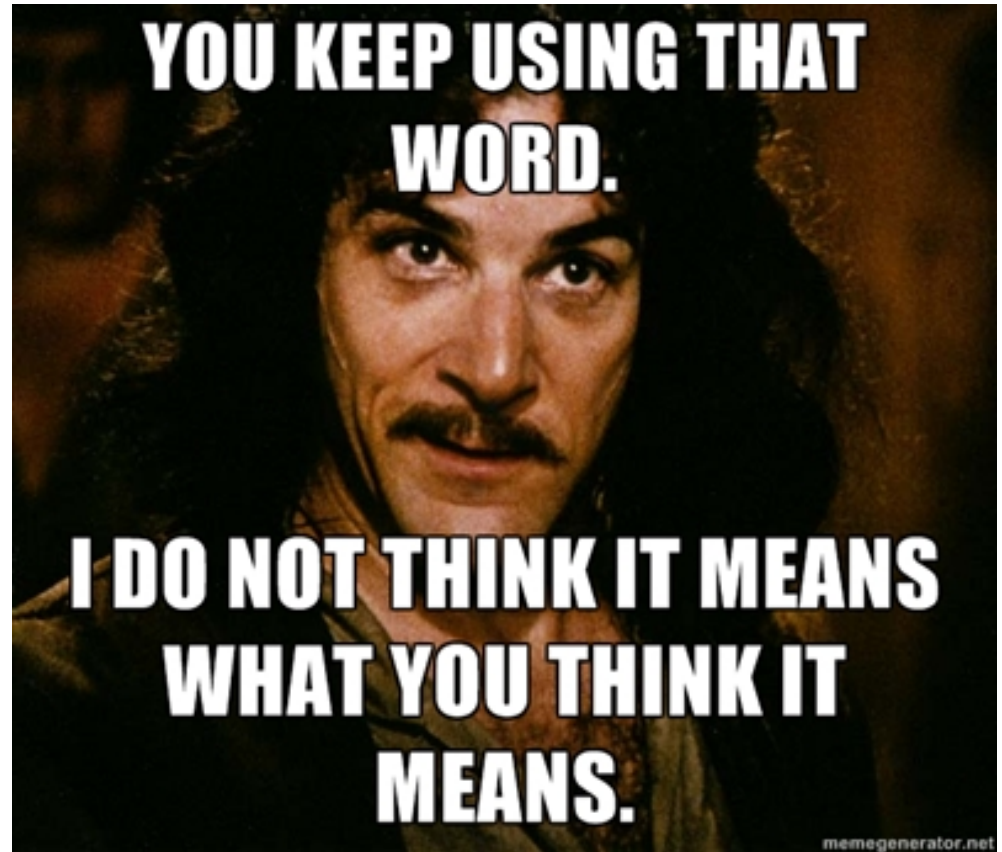


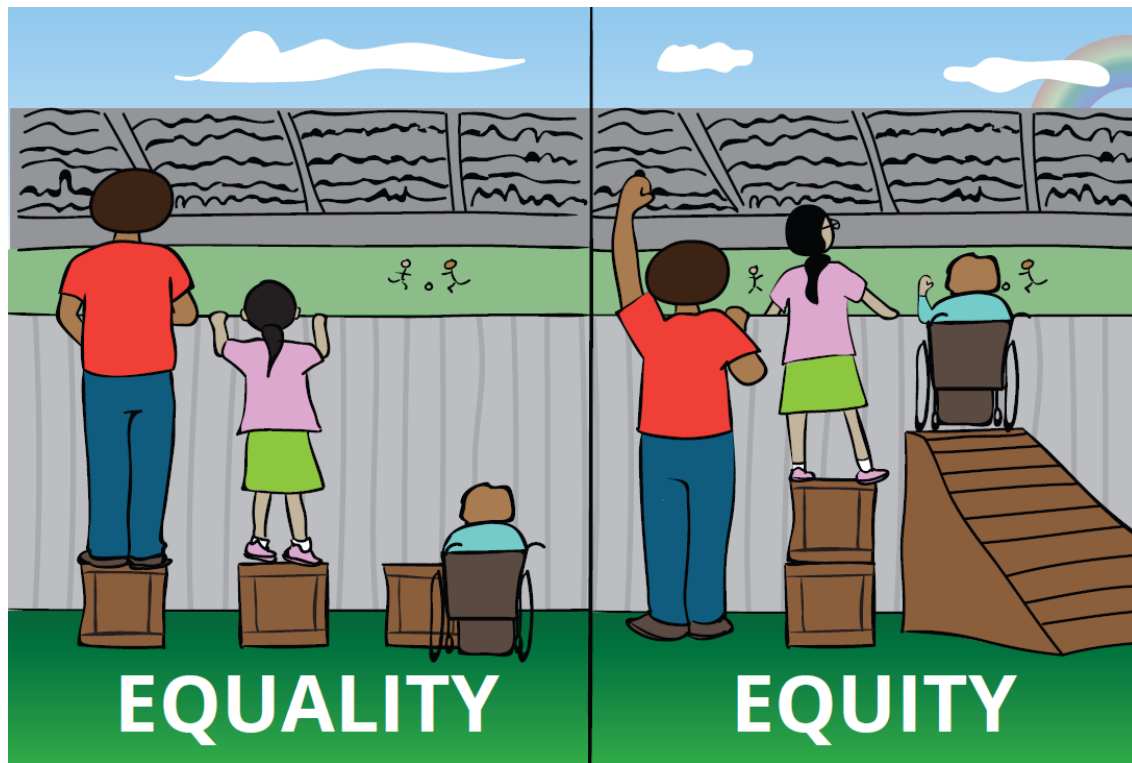
The How



## Patient Engagement

- Is it equitable?
- Is it funded?
- Is it diverse?





Is it  
equitable?



# Is it funded?



## Patient partner compensation in research and health care: the patient perspective on why and how

[Dawn P. Richards](#), *Five02 Labs and the Canadian Arthritis Patient Alliance*

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[Isabel Jordan](#), *Rare Disease Foundation*

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### Abstract

As patient and family engagement activity broadens across the continuum of care and

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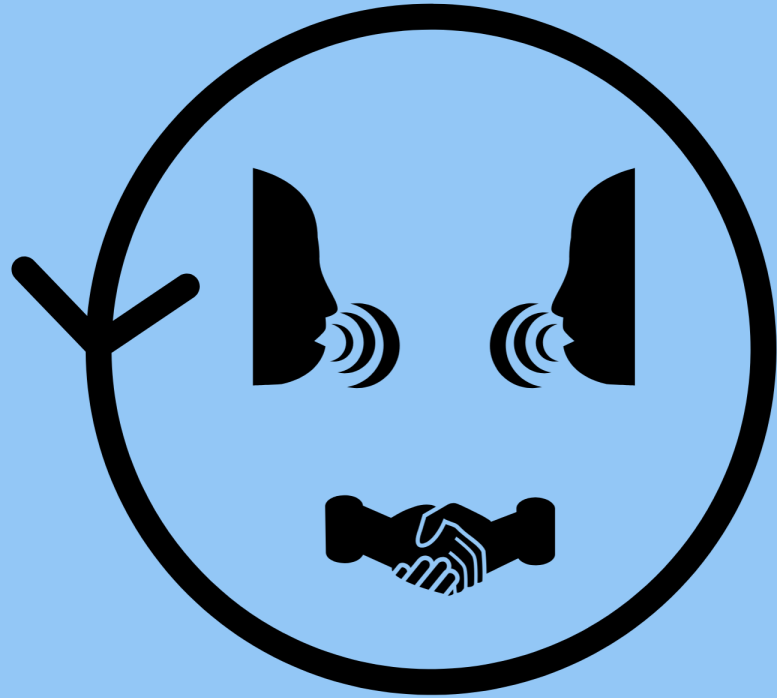
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| Is it diverse?





- Wellspring of Respect

The Goal:  
respectful  
partnership

To keep  
patient  
partnership  
from feeling  
like this  
→→



- [www.patientsincluded.org](http://www.patientsincluded.org)
- 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>
- How To Engage Patients – a crowdsourced google doc <https://sites.google.com/view/howtoengagepts/home>
- Canadian Foundation for Healthcare Improvement [Guiding Principles for Patient Engagement](#)



Respect is what I want from you  
Respect is what I need  
Respect is what I want  
Respect is what I need

