

A patient perspective: What might we be overlooking?

A risk of selection bias in our view of the field

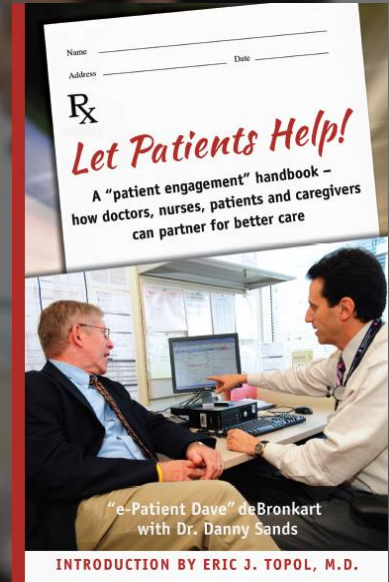
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Society for
**Participatory
Medicine**

Bringing together e-patients and health care professionals

**APCDs won't include
people who've given up
or fallen out of the system**



Dave deBronkart

@ePatientDave



"Until we have data on outcomes, won't get funding for survivorship"

[#NatlCancerForum](#)

2:34 PM - 24 Jul 2017

1 Like



1





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"Until we have data on outcomes, won't get funding for survivorship" - WHO GETS TO SAY *WHICH* OUTCOMES?

[#NatlCancerForum](#)

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"Until we have data on outcomes, won't get funding for survivorship" - WHO GETS TO SAY *WHICH* OUTCOMES? Ask pts/caregivers! [#NatlCancerForum](#)

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Go to Ground Truth

**“Who gets to say
what outcome should
be valued?”**

**“What are your goals
for your care?”**

Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions

Viet-Thi Tran , Caroline Barnes, Victor M. Montori, Bruno Falissard and Philippe Ravaud

Abstract

Background

Management strategies for patients with chronic conditions are becoming increasingly complex, which may result in a burden of treatment for patients. To develop a Minimally Disruptive Medicine designed to reduce the burden of treatment, clinicians need to understand which healthcare tasks and aggravating factors may be responsible for this burden. The objective of the present study was to describe and classify the components of the burden of treatment for patients with chronic conditions from the patient's perspective.

Methods

We performed a multi-country qualitative study using an online survey and a purposive sampling strategy to select English-, French-, and Spanish-speaking participants with different chronic conditions. Participants were recruited by physicians, patients' associations, advertisement on social media, and 'snowballing'. The answers were analyzed by i) manual content analysis with a grounded theory approach, coded by two researchers, and ii) automatic textual analysis by Reinert's method.

Results

Between 2013 and 2014, 1,053 participants from 34 different countries completed the online survey using 408,625 words. Results from both analyses were synthesized in a taxonomy of the burden of treatment, which described i) the tasks imposed on patients by their diseases and by their healthcare system (e.g., medication management, lifestyle changes, follow-up, etc.); ii) the structural (e.g., access to healthcare resources, coordination between care providers), personal, situational, and financial factors that aggravated the burden of treatment; and iii) patient-reported consequences of the burden (e.g., poor adherence to treatments, financial burden, impact on professional, family, and social life, etc.). Our findings may not be applicable to patients with chronic conditions who differ from those who responded to our survey.

“Taxonomy
of burden”

Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions

Viet-Thi Tran , Caroline Barnes, Victor M. Montori, Bruno Falissard and Philippe Ravaud

Abstract

Background

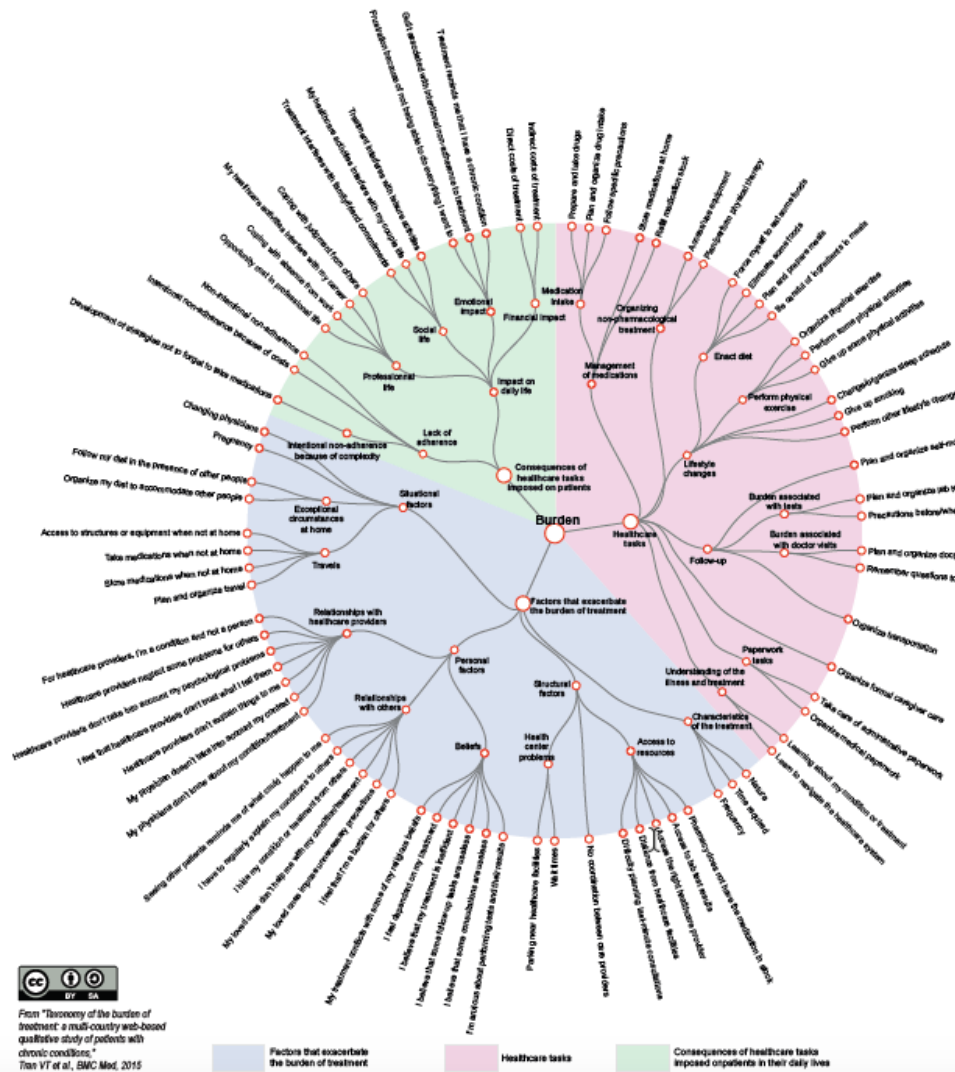
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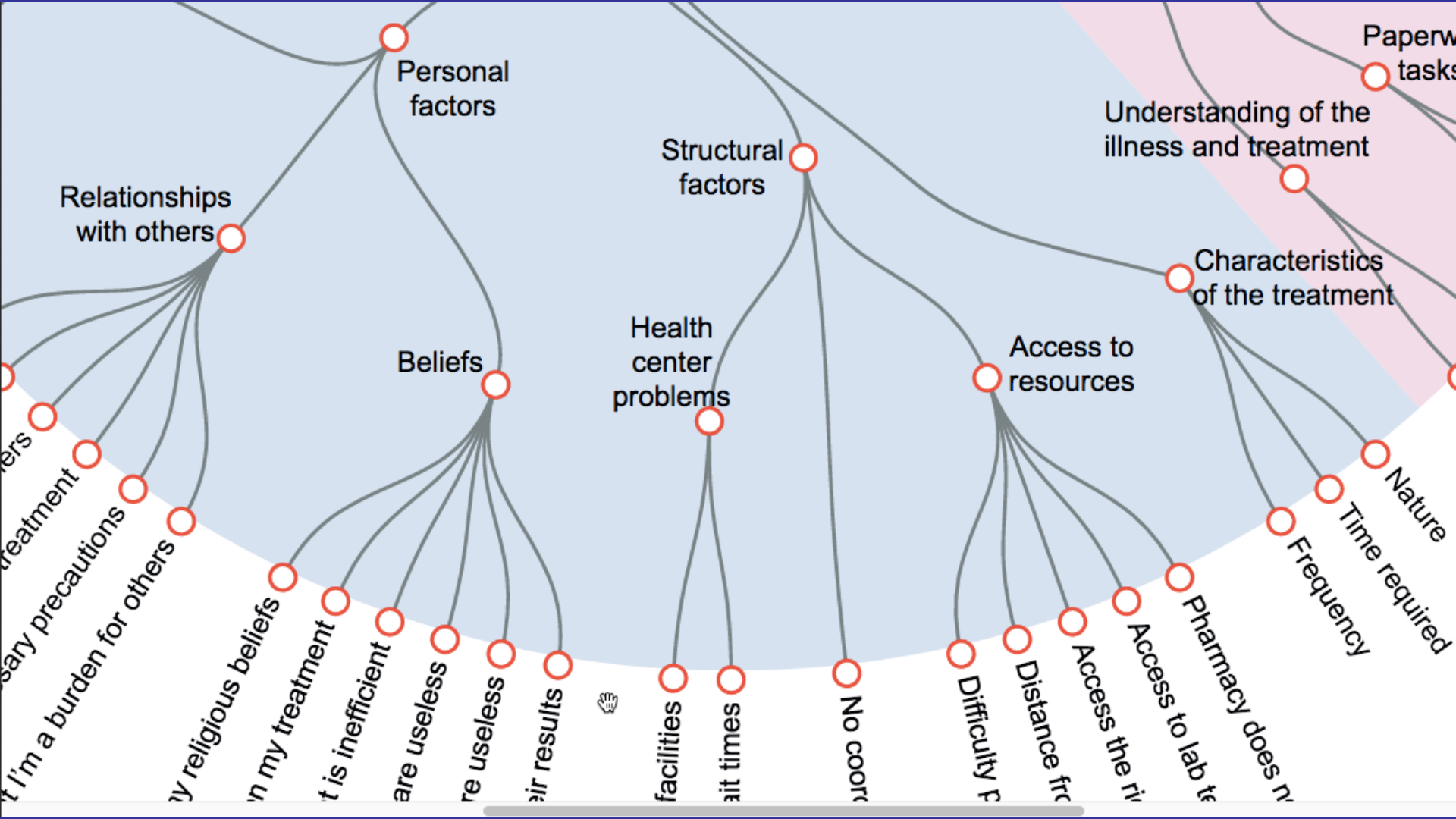
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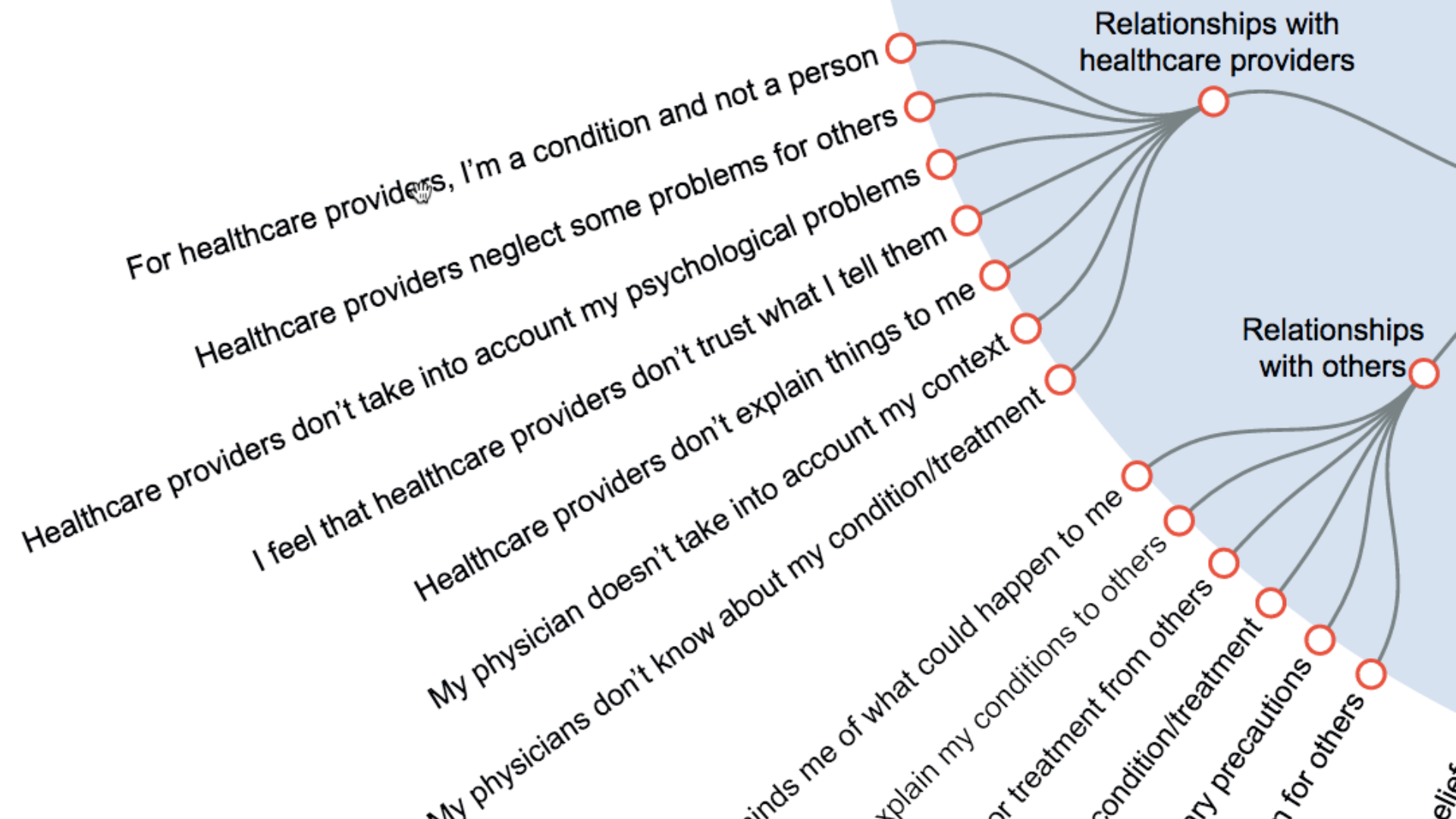
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Asking the experts

- **Kym Martin** @KymLMartin
 - Hodgkins (1983), melanoma (1992), melanoma (2004), breast cancer (2012)



Asking the experts

- **Kym Martin** @KymLMartin
 - Hodgkins (1983), melanoma (1992), melanoma (2004), breast cancer (2012)
- **Alicia Staley** @Stales
 - Hodgkins; breast cancer x2



Best Care at Lower Cost (IOM 2012)



How it actually unfolds:



How it actually unfolds:



How it actually unfolds:



This is SO not okay. It's a PROBLEM.





It's like “amenable mortality”



Transforming the Culture of Patient Care

What is Participatory Medicine? ▾

“Amenable mortality”: how well 195 countries deliver existing cures (or don't, so you die)

by Dave deBronkart | Jun 13, 2017 | 1 comment



A finding that doesn't reach the point of need is precisely like a medication with an ineffective vehicle: fruitless.

This IS a problem to the ultimate stakeholder and THIS GROUP needs to declare it and mandate that it get fixed.

**What I want you
to remember
from today:**

“This is a **PROBLEM**. We must **END** it.”



Next:
Whom should we ASK
“Is it working?”

Institute of Medicine – Sept 2012

Major new report: “Best Care at Lower Cost”

BEST CARE AT LOWER COST

The Path to Continuously Learning
Health Care in America

Institute of Medicine – Sept 2012

Major new report: “Best Care at Lower Cost”

**TABLE S-2 Characteristics of a Continuously Learning Health Care System
Science and Informatics**

Real-time access to knowledge—A learning health care system continuously captures, curates, and delivers the best available evidence to guide, support clinical decision making and care safety and quality.

Digital capture of the care experience—A learning health care system captures the care experience on digital platforms for real-time generation and application of insights for improvement.

Patient-Clinician Partnerships

Engaged, empowered patients—A learning health care system is anchored in patient perspectives and promotes the inclusion of patients, families, and other members of the continuously learning care team.

Incentives

Incentives aligned for value—In a learning health care system, incentives are aligned to promote value.

Best Care at Lower Cost says e-patients are an essential part of tomorrow's healthcare.

Patient-Clinician Partnerships

~~Engaged, empowered patients—~~

A learning health care system is
**anchored on patient needs and
perspectives**

and **promotes the inclusion** of patients,
families, and other caregivers as vital
members of the continuously learning
care team.

**What I want you
to remember
from today, #2:**

**Patients & caregivers
are the *ultimate*
stakeholder.**

**Give them veto-level
approval power.**

Analogous inhibitor: Financial toxicity

Surprise! Insurance Paid the E.R. but Not the Doctor

By MARGOT SANGER-KATZ and REED ABELSON NOV. 16, 2016



Patients who go to emergency rooms at hospitals covered by their medical plans may still receive a bill from a doctor who was not in the insurance company's network. David Goldman/Associated Press

RELATED COVERAGE



PUBLIC HEALTH
Even Insured Can Face Crushing Medical Debt, Study Finds JAN. 5, 2016



PAYING TILL IT HURTS
Costs Can Go Up Fast When E.R. Is in Network but the Doctors Are Not SEPT. 28, 2014

RECENT COMMENTS

Jesper Bernoe November 18, 2016
Nothing can surprise you in the land of P. T. Barnum.

After Surgery, Surprise \$117,000 Medical Bill From Doctor He Didn't Know

By ELISABETH ROSENTHAL SEPT. 20, 2014



Peter Drier was billed by an assistant surgeon he did not know was on his case.

Before his three-hour neck surgery for herniated disks in December, Peter Drier, 37, signed a pile of consent forms. A bank technology manager who had researched his insurance coverage, Mr. Drier was prepared when the bills started arriving: \$56,000 from Lenox Hill Hospital in Manhattan, \$4,300 from the anesthesiologist and even \$133,000 from his orthopedist, who he knew would accept a fraction of that fee.

He was blindsided, though, by a bill of about \$117,000 from an “assistant surgeon,” a Queens-based neurosurgeon whom Mr. Drier did not recall meeting.

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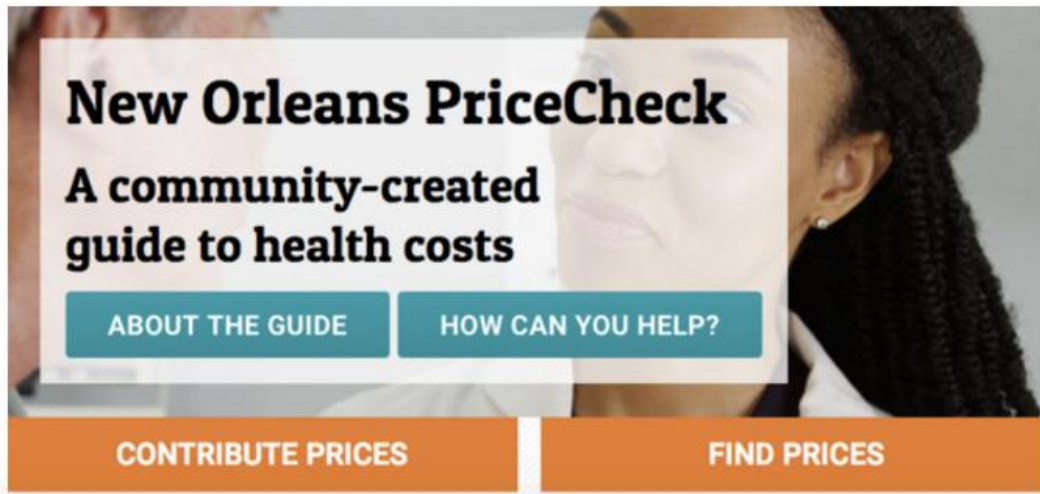
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**“We perform
better when
we’re
informed
better”**

Blood test: \$522 or \$19? MRI: \$750 or \$495? Tell us what health care is costing you

Updated on May 8, 2017 at 11:14 AM, Posted on April 5, 2017 at 5:46 AM

A banner for 'New Orleans PriceCheck' featuring a background image of a woman's face. The banner has a white central box with black text and two teal buttons. Below the white box are two orange buttons.

New Orleans PriceCheck
**A community-created
guide to health costs**

ABOUT THE GUIDE HOW CAN YOU HELP?

CONTRIBUTE PRICES FIND PRICES

Corollary:
**“It’s perverse
to keep us in
the dark and
then call us
naïve”**

Blood test: \$522 or \$19? MRI: \$750 or \$495? Tell us what health care is costing you

Updated on May 8, 2017 at 11:14 AM, Posted on April 5, 2017 at 5:46 AM

A banner for 'New Orleans PriceCheck' featuring a background image of a woman's face. The text is overlaid on a semi-transparent white box. Below the text are two teal buttons, and at the bottom are two orange buttons.

New Orleans PriceCheck
**A community-created
guide to health costs**

[ABOUT THE GUIDE](#) [HOW CAN YOU HELP?](#)

[CONTRIBUTE PRICES](#) [FIND PRICES](#)

AN AMERICAN SICKNESS



HOW HEALTHCARE BECAME
BIG BUSINESS AND
HOW YOU CAN TAKE IT BACK

ELISABETH ROSENTHAL

**What happens
when a consumer
tries to be responsible
about costs?**

N.H. insurance shopping, 2011

	Premium	Deductible	Co-pay after deductible	Max OOP (deductible + co-pay)	Stop-loss max (in-network + out)
Option A	\$894				
Option B	\$705				
Option C	\$581				
Option D	\$495				
Option H	\$624				

The choices they offered

	Premium	Deductible	Co-pay after deductible	Max OOP (deductible + co-pay)	Stop-loss max (in-network + out)
Option A	\$894	\$1,000			
Option B	\$705	\$2,500			
Option C	\$581	\$5,000			
Option D	\$495	\$10,000			
Option H	\$624	\$5,950			

The choices they offered

	Premium	Deductible	Co-pay after deductible	Max OOP (deductible + co-pay)	Stop-loss max (in-network + out)
Option A	\$894	\$1,000	20%		
Option B	\$705	\$2,500	20%		
Option C	\$581	\$5,000	20%		
Option D	\$495	\$10,000	0%		
Option H	\$624	\$5,950	0%		

The choices they offered

	Premium	Deductible	Co-pay after deductible	Max OOP (deductible + co-pay)	Stop-loss max (in-network + out)
Option A	\$894	\$1,000	20%	\$3,500	\$12,500
Option B	\$705	\$2,500	20%	\$5,000	\$12,500
Option C	\$581	\$5,000	20%	\$7,500	\$12,500
Option D	\$495	\$10,000	0%	\$10,000	n/a
Option H	\$624	\$5,950	0%	\$5,950	\$12,500

e-P

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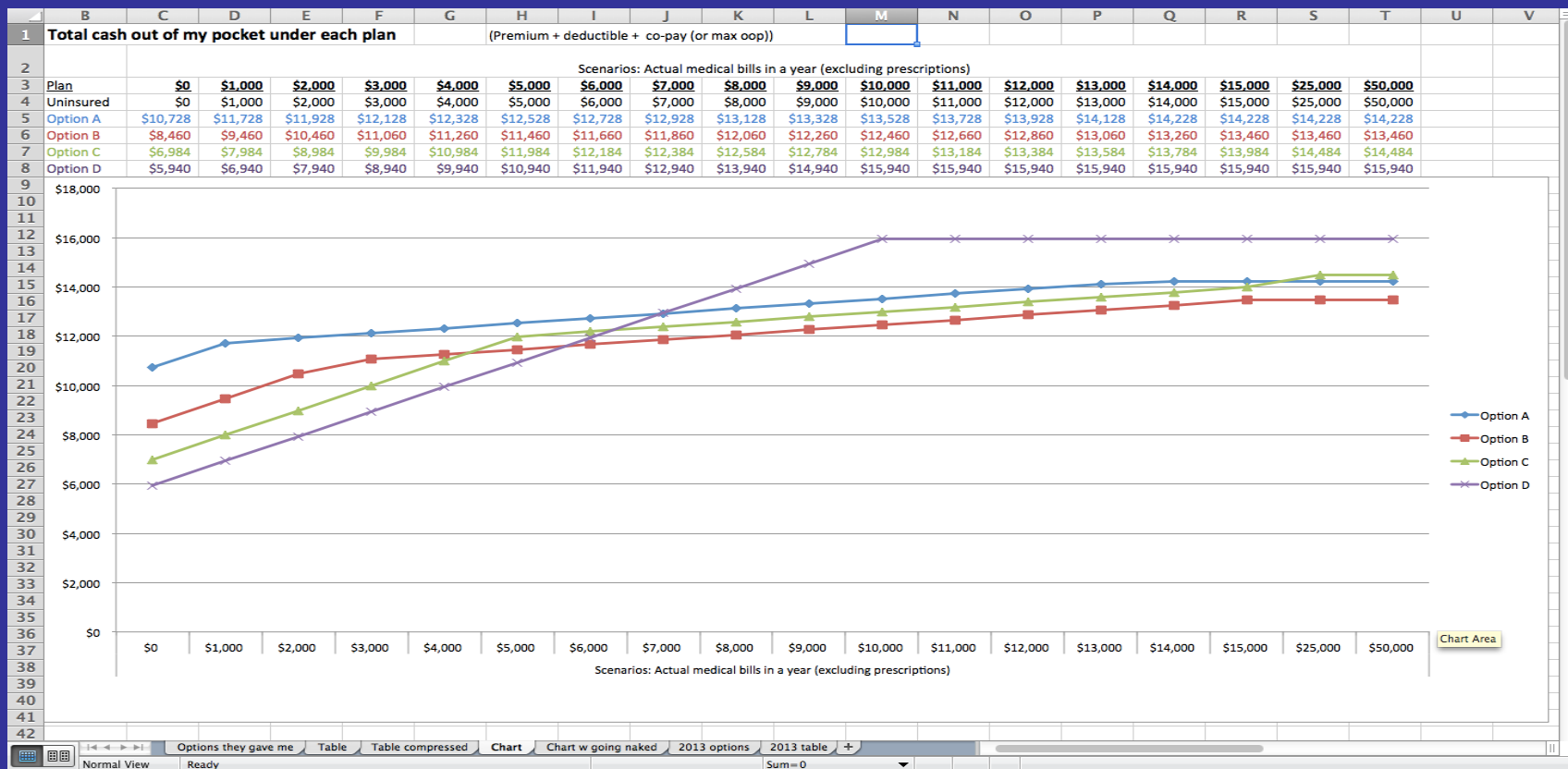
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$$=IF(\text{maxoop} < J17 + J18, \text{maxoop}, J17 + J18)$$

The screenshot displays an Excel spreadsheet titled "Calculation of my actual spending (premium + deductible + co-pay) under the 4 plan options available to me". The spreadsheet compares four insurance options: Uninsured, Option A, Option B, Option C, and Option D. The columns represent different cost components: Premium, Deductible, Co-pay after deductible, Max OOP (deductible + co-pay), Stop-loss max (in-network + out), and Actual total cost. The rows show the calculation for each option, including premiums, deductibles, co-pays, and out-of-pocket maximums. A red arrow points to the "Max OOP" column, which is highlighted in yellow. The formula bar at the top shows the formula for the "Max OOP" column: $\text{=IF(maxoop<j17+j18,maxoop,j17+j18)}$.

	Premium	Deductible	Co-pay after deductible	Max OOP (deductible + co-pay)	Stop-loss max (in-network + out)						
Uninsured			100%	\$0							
Option A	\$894	\$1,000	20%	\$3,500	\$12,500						
Option B	\$705	\$2,500	20%	\$5,000	\$12,500						
Option C	\$581	\$5,000	20%	\$7,500	\$12,500						
Option D	\$495	\$10,000	0%	\$10,000							

I know – graph it!



**My favorite
complaint:**

**“Patients are the only
ones who don’t have
any skin in the game”**

*- Practice manager, quoted in
Health Leaders, Fall 2011*

2011: EOB for a scan

*** THIS IS NOT A BILL ***

Claim: 201110240803 Patient: RICHARD D DEBRONKART Birthdate: 02/18/1950 Provider: BETH ISRAEL DEACONESS
Dates of Service: 10/03/2011-10/03/2011

Procedure Code Description	Charge	Remark Type	Remark Code	Remark Amount	Deductible	Co Ins	Co Pay	%Paid	Amt Paid	Paid to	You May Owe
HOSPITAL	17.00	PPO Discount	1	5.78	11.22	.00	.00		.00	N/A	11.22
HOSPITAL	36.00	PPO Discount	1	12.24	23.76	.00	.00		.00	N/A	23.76
HOSPITAL	24.00	PPO Discount	1	8.16	15.84	.00	.00		.00	N/A	15.84
HOSPITAL	25.00	PPO Discount	1	8.50	16.50	.00	.00		.00	N/A	16.50
HOSPITAL	35.00	PPO Discount	1	11.90	23.10	.00	.00		.00	N/A	23.10
HOSPITAL	47.00	PPO Discount	1	15.98	31.02	.00	.00		.00	N/A	31.02
HOSPITAL	24.00	PPO Discount	1	8.16	15.84	.00	.00		.00	N/A	15.84
HOSPITAL	28.00	PPO Discount	1	9.52	18.48	.00	.00		.00	N/A	18.48
HOSPITAL	24.00	PPO Discount	1	8.16	15.84	.00	.00		.00	N/A	15.84
HOSPITAL	49.00	PPO Discount	1	16.66	32.34	.00	.00		.00	N/A	32.34
HOSPITAL	67.00	PPO Discount	1	22.78	44.22	.00	.00		.00	N/A	44.22
HOSPITAL	1,433.00	PPO Discount	1	487.22	945.78	.00	.00		.00	N/A	945.78
HOSPITAL	440.00	PPO Discount	1	149.60	290.40	.00	.00		.00	N/A	290.40
HOSPITAL	191.00	PPO Discount	1	64.94	126.06	.00	.00		.00	N/A	126.06
HOSPITAL	191.00	PPO Discount	1	64.94	126.06	.00	.00		.00	N/A	126.06
	2,631.00			894.54	1736.46	.00	.00				1736.46

DEDUCTIBLE/OUT OF POCKET SUMMARY

Individual/Family Total	Year	Description	Satisfied
RICHARD D	2011	MAJOR MEDICAL DED	1736.46

Code	Reference Description
1	This amount represents the First Health PPO discount. Patient's not responsible
1	for amount.



Speaking of skin in the game...

Time to practice what I preach: I have skin cancer again.



Photo of the lesion, Nov. 15 (click to enlarge, if you really want)

Update Feb. 11: I've decided to publish what I want to find in a provider: see [this post](#).

Be sure too to read the substantial information contributed below in comments, some by e-patients and some by participatory providers. This process is interesting to observe!

An odd consequence of speaking at medical conferences is that sometimes my face is displayed, *real big*, on monitors at the front of a room. That happened in November at the Aligning Forces for Quality (AF4Q) annual meeting in Washington.

At the end, Lisa Letourneau MD, MPH of [Maine Quality Counts](#) raced up, pointed to my jaw, and said "You should have that checked. I think it's a basal cell." (That's the least serious type of skin cancer – see [Wikipedia](#): "**Basal-cell carcinoma** (BCC) is the most common type of [skin cancer](#). It rarely [metastasizes](#) or kills.") A few days later I took the picture at left, and started watching.

I had a basal cell removed from my nose 30+ years ago. (More on this in a moment.)

To me it was just a shaving cut... but, I realized, it wouldn't heal. For the next two months I was a slug (a not-engaged patient!), but I did take pictures, and son of a gun it did not get better, even when I thought it was finally going away.

When I had my annual physical recently, I asked my doctor, and he looked and said, "Get a biopsy." I did, this week, and today they called. Yup, it's a basal cell. Thanks, Dr. L!

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Patient Safety

Doing what empowered buyers do

dave.pt/skincancerRFP

Home > Boot Camp! < Schedule For Patients Pt. Communities For Providers Videos Boards & Awards Media

I've started an RFP for my skin cancer

The other day [I announced](#) my new skin cancer diagnosis and discussed how I'll blog my approach to it as an e-patient.

I've decided to explore my options by doing what companies do when they're shopping for a solution: they write a Request for Proposals, and let vendors reply. But in this case what I published isn't cast in stone – I invite discussion and suggestions. And, significantly, I start with the context: partnership; participatory medicine –

I'm approaching this through an RFP process because I believe in "participatory medicine," in which patients play an active and responsible role in all aspects of healthcare. I believe patients should play an active role in making care more cost-effective and patient-centered, by being responsible about costs and by saying what

Request for Proposals: remove a basal cell carcinoma

First version 9 a.m. ET 2/11/2012. Minor edits 12:37 pm. Some additions labeled 8:30 pm.

Client: Dave deBronkart

Primary physician: Daniel Z. Sands, MD, MPH, Beth Israel Deaconess (BID), Boston

Summary: I seek a care partner to remove a basal cell carcinoma (BCC) from my left jawline, under the ear. For a brief introduction, see blog post and photo (low quality) at <http://davept.blogspot.com/2012/02/dave-bcc.html>.

I'm educating myself about the condition, I want to explore the available treatment options, and I'm "shopping" for a partner to do the work and follow-up with a good combination of quality, partnership, and cost.

Responses and questions to: rfp@epatientdave.com

Introduction: Partnership

The context for this exercise is responsible partnership between patient and provider, with open discussion of wants and of what works for each.

Participatory medicine:

I'm approaching this through an RFP process because I believe in "participatory medicine," in which patients play an active and responsible role in all aspects of healthcare. I believe patients should play an active role in making care more cost-effective and patient-centered, by being responsible about costs and by saying what

“p” = professional charge only; all other prices include facility charge (“f”) if any						
	Facility 1		Facility 2		Facility 3	
Mohs	CPT	Cost	CPT	Cost	CPT	Cost
Stage 1	17311	\$2000 (\$1444p)	17311	\$1900; allowable: \$4597	17311	\$1904 (\$1,178p)
Additional stages	17312	(\$673p)\$1600	17312 -15	\$1400	17312	\$1752 (\$627p)
Total if 3 stages		\$5200		\$4700		\$5408
Pathology billing		May cost extra	No extra			May cost extra
Closing – simple	Intermed: 12051	\$552	12001-	\$900	12001-18	\$1246 (\$278-\$686p)
Closing – complex		\$2700	12018	\$2900	12051	\$1246 (\$492p)
Total – Minimum / simplest case		\$2000 + 552 \$2552		\$ 200 \$1900 <u>\$ 900</u> \$3000		\$1904 <u>\$1524</u> \$3428
Total cost for 3 stages and medium repair		\$5200 +\$1600 \$6800		\$ 200 \$4500 +\$1900 \$6600		\$5408 +\$1738 \$7146

Obstacle to adoption:
**“My patients
aren’t asking
for this.”**

Why don't patients behave like consumers?

TEDMED2012 Jon Cohen



*Vote NO
on Woman Suffrage*

dupl
Household Hints



S

BECAUSE 90% of the women either do not
want it, or *do not care*.

th
BEC/
ra
BEC/
th
u
BECAUSE 80% of the women eligible to vote
are married and can only double or annul
their husbands' votes.

BECAUSE it is unwise to risk the good we
already have for the evil which may occur.

Votes of Women can accomplish no more
than votes of Men. Why waste time,
energy and money, without result?

A patient perspective: What might we be overlooking?

A risk of selection bias in our view of the field

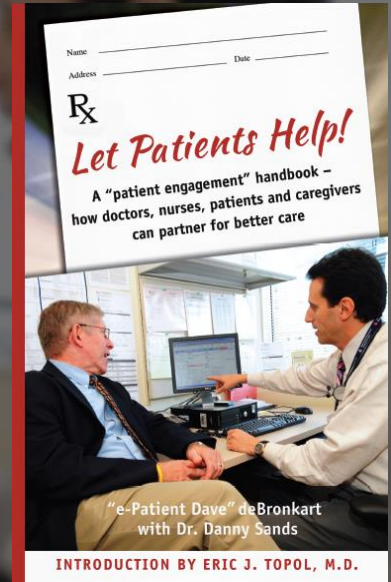
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dave@epatientdave.com



Society for
**Participatory
Medicine**

Bringing together e-patients and health care professionals