



**Improving Patient Experience:
What's Working, What's Not**



October 6, 2016

Dial In: 877.668.4493
Code: 668 207 242





Having Audio Issues?

If you experience any disruptions or other issues with audio during today's WIHI, we ask that you:

- Notify WIHIAdmin through the WebEx chat
- If the problem persists, notify IHI Customer Service at 617.301.4800 or info@ihi.org

Download resources and slides when you log off or next day on IHI.org/WIHI

Dial In: 877.668.4493

Code: 668 207 242





Madge Kaplan, IHI's Director of Communications, is responsible for developing new and innovative means for IHI to communicate the stories, leading examples of change, and policy implications emerging from the world of quality improvement — both in the U.S. and internationally. Prior to joining IHI in July 2004, Ms. Kaplan spent 20 years as a broadcast journalist for public radio – most recently working as a health correspondent for National Public Radio. Ms. Kaplan was the creator and Senior Editor of Marketplace Radio's Health Desk at WGBH in Boston, and was a 1989/99 Kaiser Media Fellow in Health. She has produced numerous documentaries, and her reporting has been recognized by American Women in Radio and Television, Pew Charitable Trusts, American Academy of Nursing and Massachusetts Broadcasters Association.

For resources & slides, visit IHI.org/WIHI

Dial In: 877.668.4493
Code: 668 207 242





Martha Donovan Hayward, Institute for Healthcare Improvement (IHI) Faculty and Patient Advisor, is focused on bringing patients and families into the design of all work to accelerate improvement of health care delivery. She has served as the Lead for Public and Patient Engagement at IHI since March 2011 . A cancer survivor herself, she is a founding board member of the nonprofit Women’s Health Exchange and served on the Patient and Family Advisory Council of Dana-Farber Cancer Institute in Boston. Prior to joining the health care world Martha enjoyed a 20 year career communications, marketing and fundraising in the areas of health, politics, and education. In her faculty role with IHI, she speaks and teaches programs including Patient Safety Officer Training, Executive Development, Strategic Partners and Patient Experience Seminars. Martha has offered keynote addresses on the subjects of Patient and Family Centered Care, Patient Engagement, and End of Life Care to local, regional and national audiences.

You can reach Martha at Mhayward@Ihi.org

For resources & slides, visit IHI.org/WIHI

Dial In: 877.668.4493
Code: 668 207 242





Cody Mullen, PhD(c), is the network development coordinator for the Indiana Rural Health Association (IRHA) facilitating the development of chronic care management program supporting citizens within rural Indiana to help lower the cost and improve quality of care for individuals. In addition, Cody supports the research activities of IRHA. Cody earned his BS from Purdue University in Interdisciplinary Science with a focus on healthcare engineering and statistics. Cody is currently a doctoral candidate in Health Policy and Management at the Richard M. Fairbanks School of Public Health with research interests in quality of care and access to care for vulnerable populations, especially citizens of rural America and individuals with an intellectual/developmental disability.

You can reach Cody at Cmullen@indianarha.org

For resources & slides, visit IHI.org/WIHI

Dial In: 877.668.4493
Code: 668 207 242





Robert B. Doherty is Senior Vice President of Governmental Affairs and Public Policy for the American College of Physicians (ACP), the largest physician specialty society and second largest medical organization in the United States. ACP represents 148,000 internal medicine physicians and medical student members. Mr. Doherty has more than 37 years of health policy experience and is an accomplished presenter at health conferences. From 1979 to 1998, Mr. Doherty worked in the governmental affairs department of the American Society of Internal Medicine, and with the merger of ASIM and ACP in June, 1998, joined the ACP as Senior Vice President for Governmental Affairs and Public Policy. He has senior staff management responsibilities for ACP's Division of Governmental Affairs and Public Policy, located in Washington, D.C. Mr. Doherty has authored or co-authored many policy-related papers for the *Annals of Internal Medicine*, ACP's flagship peer-reviewed journal, and writes and hosts The ACP Advocate Blog with Bob Doherty, the winner of the 2009 Best Health Policy/Ethics Blog in an award program sponsored by Epocrates. He writes a monthly "Washington Perspectives" column in *The ACP Internist*. He also is a guest blogger for the Philadelphia Inquirers' Health Cents blog.

For resources & slides, visit IHI.org/WIHI

Dial In: 877.668.4493
Code: 668 207 242

You can reach Robert at rdoherty@mail.acponline.org



Jess Jacobs, upbeat empowered patient and Aetna innovator, dies

By NEIL VERSEIL

7 Comments / 440 Shares / Aug 15, 2016 at 8:00 AM



Jess Jacobs

Jessica "Jess" Jacobs, a young but accomplished director in Aetna's Innovation Labs and a dynamic advocate for herself and other patients, has died. She was 29, sources said.

Jacobs fought both an autonomic disorder called postural orthostatic tachycardia syndrome (POTS) and a rare hereditary disease of connective tissue called Ehlers-Danlos Syndrome (EDS). Friends labeled her a "unicorn," based on the long odds against having two such debilitating diseases.

Jacobs died Saturday in California. She had moved back to her home town of Twain Harte, California, from Washington, D.C., in June to be closer to her family.

A tweet chat held in her memory Sunday evening had the hashtag #Unicorn.jess. Participants said the hashtag was No. 2 on their personal Twitter trending lists after "Bolt"; Jamaican sprinter Usain Bolt won his third consecutive Olympic gold medal in the 100-meter race while the chat was going on.

A former U.S. Department of Health and Human Services employee, Jacobs co-founded the Health IT Council in the Food and Drug Administration's Center for Drug Evaluation and Research, according to her LinkedIn profile. She also wrote the promotional plan for the Text4Health messaging program on behalf of the Health Resources and Services Administration.

She regularly tweeted and blogged about her many hospital stays, including her poor experiences. Jacobs, a green belt in Six Sigma, once rated a 12-hour wait in the ER for a hospital bed as having 7 percent process cycle efficiency.

Jacobs was tweeting from the hospital right up until Friday about her frustrations with the healthcare system.

GOT NEWS? SEND US A TIP



MedCity
ENGAGE
OCTOBER 18-19, 2016 • SAN DIEGO

Connect with
healthcare innovators
disrupting patient engagement.

Register — Save Now

PROMOTED

Join us at ENGAGE, MedCity News' Patient Engagement Summit

Discover best-in-class patient engagement strategies at MedCity ENGAGE, held October 18-19 in San Diego. Meet and connect with experts and innovators from across the healthcare ecosystem that are changing the landscape of patient engagement. Register now and save. Find out more here.

MEDCITY NEWS

MedCity Inbox

Get the latest in this area in your inbox when you subscribe to our daily newsletter.

Your email address

TELEMEDICINE →

Startup TreatMD sets sights on global

Signs bet big on telehealth, Aetna on Apple Watch

15 Nov

On Wasting My Time – The Numbers

Posted by: [jessjacobs](#) | Categories: [The Patient](#) [The Posts](#) 118 Comments

If you've wondered why I've been under the radar lately, look no further than my odyssey of medical maladies; in addition to my ongoing struggle with POTS, this year I've had: a kidney infection, shingles, pneumonia, a pulmonary embolism, and four blood transfusions. Since I'm a numbers person, I downloaded my claims data from my insurer to get a better idea of how much time I've wasted in the healthcare system since January 2014.

Useful Visits

This last year I had 56 outpatient doctor visits, 20 emergency room visits, and spent 54 days inpatient. But how many of these visits were useful? As you can see in the table below, not many.

	Total Visits	Useful Visits	Useful Visits	Useless Visits
Outpatient				
Cardiology	7	3	43%	57%
Endocrinology	1	1	100%	0%
Gastroenterology	6	2	33%	67%
Hematology	2	1	50%	50%
Neurology	1	0	0%	100%
Ophthalmology	1	1	100%	0%
Pain Specialist	8	3	38%	63%
Primary Care	15	2	13%	87%
Psychology	11	2	18%	82%
Rheumatology	4	0	0%	100%
	56	16	29%	71%
Inpatient				
Emergency Room	20	9	45%	55%
Hospitalizations	9	8	89%	11%
Hospital Days	54	10	19%	81%
Ambulance	7	3	43%	57%

I used the following definitions of 'useful':

Recent

- » On the Worst Healthcare Experience of My Life May 31, 2015
- » On Wasting My Time – The Numbers November 15, 2014
- » How I stopped worrying (about my Klout score) and learned to love The Twitter July 3, 2014
- » On Climbing Mountains April 28, 2014
- » On Being Rare February 28, 2014

Engage

- » [Wen Dombrowski MD \(@HealthcareWen\)](#) on On Being Rare
- » [@markwwilsonmd](#) on On Being Rare
- » [Jess Jacobs \(@jess_jacobs\)](#) on On Being Rare
- » [Jess Jacobs \(@jess_jacobs\)](#) on On Being Rare
- » [@jrmcnulty](#) on Health IT and the Care Continuum: Engaged Exchange of Health Information

So yes, I owe the medical system my life for giving me blood when my hemoglobin drops deathly low.

But there's no reason a 4 hour transfusion required 84 hours of negotiation and frustration.

There's no reason that only 4.75% of outpatient visits and .08% of my hospitalizations are spent actively treating my condition. There's no reason that I spent two solid months (1540 hours, 64.2 days) of this year waiting instead of healing.

So, please, stop wasting my time. Stop wasting my life.

31
May

On the Worst Healthcare Experience of My Life

Posted by: [jessjacobs](#) | Categories: [The Hypocrisy](#) [The Patient](#) [The Posts](#) 67 Comments

I've now spent two consecutive Memorial Day weekends at Hospital X with intractable vomiting. Last year I checked myself in. This year, I took the scenic route via three weeks of hard time at Hospital A followed by a transfer to Hospital X. When the nurse blindsided me with the transfer order to Hospital X after COB on a Friday night, I assumed it was a clerical error. The plan that'd been laid out by my primary hospitalist team was to transfer me to a hospital which specializes in CVS. When my (new) weekend hospitalist had run by for +/- 90 seconds Friday morning, he'd said I'd be transferred Monday as planned.

But here I was, 8 hours later, hysterically crying over the prospect of being sent back to the hell which is Hospital X. I finally got nursing to call the hospitalist so I could plead with him to change the order. I let him know that Hospital X's 'care' is better characterized as psychological and physical torture. I firmly believe I am better off facedown in a ditch, drowning in an inch of muddy water, than under the care of Hospital X. The hospitalist attempted to contain his exasperation while insisting that ditches are a far worse fate than Hospital X and I am lucky he had managed to secure a transfer to a new cyclic vomiting specialist there. I've now been admitted for 8 days at Hospital X and haven't seen anyone from the GI department, let alone a CVS specialist. I have, however, been told by hospital police that they would cuff me and take me to jail for taking photos of them ransacking my belongings following a syncopal episode. This egregious treatment doesn't surprise me - indeed, last month I wrote Hospital X a letter of complaint, copied below, which shared how their lack humanity has broken my spirit.



Caught by the Scruff of my Neck | Manometry w/ RSV | Mistaking Hand Sanitizer for Mouth Wash | Central Line Infection | 50 Needle Sticks | Broken Femur

Dear Dr. X-

Thank you for your willingness to contact me, the patient in question, regarding my experience with Hospital X. Apologies for the lapse in time, your email disappeared to the bottom of my inbox when I was readmitted to Hospital A with a central line infection. My choice to return to the facility which gave me the infection, instead of coming to Hospital X, is a good indication of the disdain with which I hold your hospital with.

When Dr. Y visited me during a two-week stay in July, I thought Hospital X had hit rock bottom. During this stay my roommate's bloody vomit sat clogged in the sink for three days before someone came to plunge it. Sanitary conditions pale in comparison to the forced separation from my friend and advocate who is a Medical Student with your facility. While I fully understand the need to keep relationships between students and patients professional to protect patient privacy/health and their education... Over the years my friend has come to know my health likely better than I do... and long ago I legally gave them permission to access my medical information [so any professional/educational distance is null].

Recent

- » On the Worst Healthcare Experience of My Life May 31, 2015
- » On Wasting My Time – The Numbers November 15, 2014
- » How I stopped worrying (about my Klout score) and learned to love The Twitter July 3, 2014
- » On Climbing Mountains April 28, 2014
- » On Being Rare February 28, 2014

Engage

- » Wen Dombrowski MD (@HealthcareWen) on On Being Rare
- » @markwwilsonmd on On Being Rare
- » Jess Jacobs (@jess_jacobs) on On Being Rare
- » Jess Jacobs (@jess_jacobs) on On Being Rare
- » @jrncnulty on Health IT and the Care Continuum: Engaged Exchange of Health Information

Archive

Archive

I've experienced many horrible things during my healthcare journey. I have experienced pain – I broke my femur in a remote location and spent hours in transit before receiving pain medication. I have experienced makeshift environments - last September I spent 27 hours in a hallway waiting for a bed to open while being treated for a pulmonary embolism. But this experience of complete powerlessness in the face of another's pain is, bar none, the most profoundly heartbreaking experience of my life.

During this situation, I contacted the patient advocate several times via email/phone and complained in person post discharge. While I am appreciative of Dr. Y for bringing these issues to your attention and find your immediate response very encouraging, it saddens me that as a simple patient my voice wasn't heard.

ACP Advocacy Blog

The ACP Advocacy Blog is written by Bob Doherty and maintained by the American College of Physicians. Refer to the blog articles for the latest in issues important to Internists.

About the Author

Bob Doherty is Senior Vice President, American College of Physicians Government Affairs and Public Policy; Author of the ACP Advocate Blog

Email Bob Doherty:
TheACPAdvocateblog@acponline.org

Follow @BobDohertyACP

Share



Blog Archive

- ▼ 2016 (13)
 - ▼ August (2)
 - [Patient-centered care? Not for this patient . . .](#)
 - [Make it go away!](#)
 - July (2)
 - June (2)
 - May (1)
 - April (1)
 - March (2)
 - February (1)
 - January (2)
- 2015 (30)
- 2014 (29)
- 2013 (43)
- 2012 (60)
- 2011 (69)

Wednesday, August 17, 2016

Patient-centered care? Not for this patient . . . and not for how many more?

Although I didn't know Jess Jacobs, a young woman who tragically died on Monday after suffering for years from two rare diseases, I have learned much about her from [her blogs](#) detailing her encounters with the healthcare system.

I have learned that she suffered greatly from her conditions, [postural orthostatic tachycardia syndrome \(POTS\)](#), an autonomic disorder, and from [Ehlers-Danlos Syndrome \(EDS\)](#), a rare hereditary disease of connective tissue.

I learned that her suffering was unnecessarily compounded by a health care system that, by her own detailed reports, failed her at every point.

On February 14, 2014, she wrote of her [frustrations](#) over receiving the following letter from her primary care physician:

Hi Jess,

POTS is a rare diagnosis, and I am by no means a specialist in the treatment of it. I cannot comment on whether treatment with opioids is the best route or not. My only suggestion was that it might be prudent to see another POTS specialist for an opinion. It might also turn out to be helpful to see the Rheumatologist and Neurologist to see if they have any thoughts or ideas.

I know this is beyond frustrating for you, feeling poorly and not having any therapies pan-out with respect to making you feel better. There are no clear answers when it comes to POTS.

Best wishes,

Primary Care Physician

Jess's reply, excerpted below, takes the doctor on for "surrendering" rather than trying to coordinate her care:

The majority of my friends are allied with the healthcare field – doctors, health lawyers, nurses, health administrators – and all ask "who's coordinating all of this?" to which I say I am and then they all stress about who is going to take over when I start puking and can't get off the floor on my own.

I'm not sure where they got the notion that my primary care physician should coordinate my care, maybe they were looking at NCQA's patient centered medical homes model, or found a copy of the Accountable Care Organization regulations from CMS, or listened to people discuss Obamacare on Late Night with Jimmy Fallon. All I know is that they all say that a PCP is the person to coordinate care.

In my search to figure out what this actually means, a physician friend turned me onto Vernon Wilson's 1969 article entitled "Prototype of a Doctor." Wilson postulates that as a continuing medical advocate for their patient, a PCP's job is to evaluate and coordinate patient care and "accept responsibility not merely pass it along – utiliz[ing] specialists rather than surrendering to them."

By telling me that my condition is complex and stating that I should just see additional specialists, you are surrendering. . . So, this leads me to ask: If you are not willing and able to help me, who in your practice is?

Best,

Jess



Health — Health Cents

Patient-centered care is all the rage. But why are so few patients receiving it?

Updated: AUGUST 30, 2016 — 4:00 AM EDT

by Robert B. Doherty, Senior Vice President of Governmental Affairs & Public Policy American College of Physicians

You would think that healthcare should be all about the patient, right? But in fact, it's long been recognized that patients often are treated like an after-thought by our health care system. Whether it is overly complex billing systems, lack of transparency in quality and cost, fragmented and uncoordinated care, or hurried, harried and inattentive clinicians, our healthcare system seems to be more about meeting the needs of everyone *but* the patient.

This is not a new problem. About 10 years ago, recognition that healthcare was failing so many patients led to a movement, called *patient-centered care*, to institute reforms to put patients in the driver's seat. A 2008 [research paper](#) describes the following six core elements of patient-centered care:

To learn more:

- Jess' blog: <http://jessjacobs.me/>
- My ACP Advocate blog:
<http://advocacyblog.acponline.org/2016/08/patient-centered-care-not-for-this-17.html>
- My Philadelphia Inquirer Health Cents blog:
<http://www.philly.com/philly/blogs/health-cents/Patient-centered-care-is-all-the-rage--So-why-are-so-few-patients-receiving-it.html>



Cheri C. Wilson, MA, MHS, CPHQ is a nationally recognized diversity and inclusion, cultural and linguistic competence, and health equity subject matter expert, who is also a highly regarded public speaker and trainer. She served as the Director, Corporate Office of Diversity and Inclusion at RWJ Barnabas Health, the largest health system in New Jersey. In May 2010, Ms. Wilson was appointed a Faculty Research Associate in the Department of Health Policy and Management in the Johns Hopkins Bloomberg School of Public Health, Hopkins Center for Health Disparities Solutions and was promoted to Assistant Scientist in February 2014. Previously, she was an Acting Assistant Director of the Quality Improvement Department at The Johns Hopkins Hospital. Ms. Wilson is a Certified Professional in Healthcare Quality (CPHQ), a Past President of the Maryland Association for Healthcare Quality (MAHQ) (2009), and a Lean Six Sigma Green Belt. She is particularly interested in health and healthcare disparities and health equity as they relate to racial/ethnic, language, and gender and sexual minorities and the provision of culturally competent patient-centered care in language understandable to all patients.

You can reach Cheri at cwilson366@comcast.net

For resources & slides, visit IHI.org/WIHI

Dial In: 877.668.4493
Code: 668 207 242



How do we measure the patient experience?

- Almost sole reliance upon patient experience surveys:
 - HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems)
 - CAHPS (Consumer Assessment of Healthcare Providers and Systems)
 - American Indian, Clinician & Group, Dental Plan, Experience of Care & Health Outcomes, Health Plan, Home Health Care, In-Center Hemodialysis, Nursing home, Outpatient and Ambulatory Surgery, Surgical Care

Who responds to your patient experience surveys?

- Review response rates not only in the aggregate, but by group:
 - Racial/ethnic
 - Language
 - Age
 - Socioeconomic status (insurance status or zip code as a proxy)
 - LGBT
 - Level of education

Are patients receiving surveys in their preferred language?

- HCAHPS
 - Mail
 - English, Spanish, Russian, Chinese, Vietnamese, Portuguese
 - Telephone
 - English and Spanish
 - Interactive Voice Response
 - English and Spanish
- CAHPS
 - English and Spanish
 - AHRQ recommendations for translating into other languages

Stratify patient experience data

- In addition to reviewing response rates, stratify question responses by group and review for differences/disparities:
 - Racial/ethnic
 - Language
 - Age
 - Socioeconomic status (insurance status or zip code as a proxy)
 - LGBT
 - Level of education

Enhancing Survey Instruments: Supplemental Items (Customized Surveys)

- HCAHPS (Adult)
 - Health literacy
 - Information about medications
 - Communication between nurses and patients
 - Communication between doctors and patients
 - Communication about tests
 - Communication about forms
 - Information about how to care for yourself at home
 - Interpreter services

Enhancing Survey Instruments: Supplemental Items (Customized Surveys)

- CAHPS Clinician & Group (Adult)
 - Access
 - Patient-Centered Medical Home
- CAHPS Clinician & Group (Child)
 - Access
 - Patient-Centered Medical Home

Take Home Points

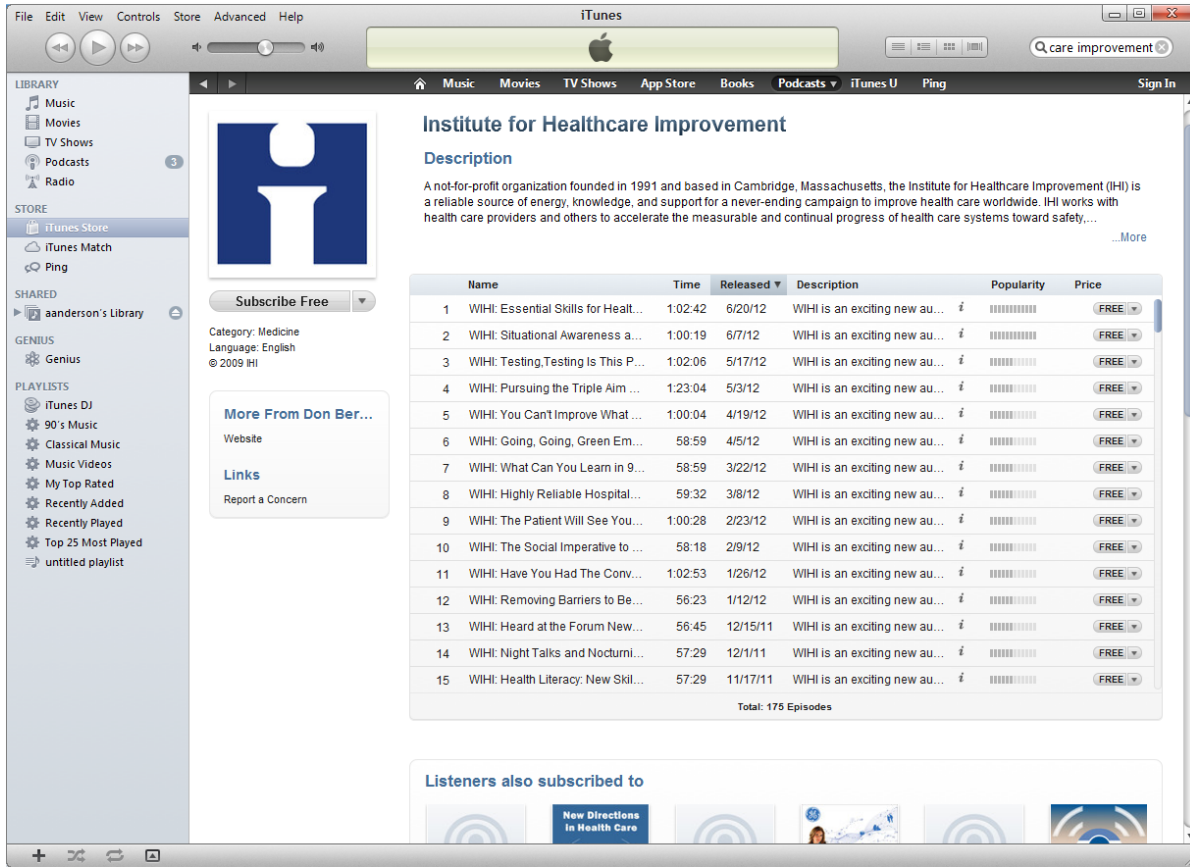
- Review Response rates
- Administer surveys in the patient's preferred language
- Stratify data by demographic characteristics
- Identify differences/disparities and opportunities for improvement
- Enhance survey instruments with supplemental items = customized surveys



28th Annual
National Forum
on Quality
Improvement in
Health Care

December 4-7
Orlando, FL

Find Us at iTunes®



Institute for Healthcare Improvement

Description

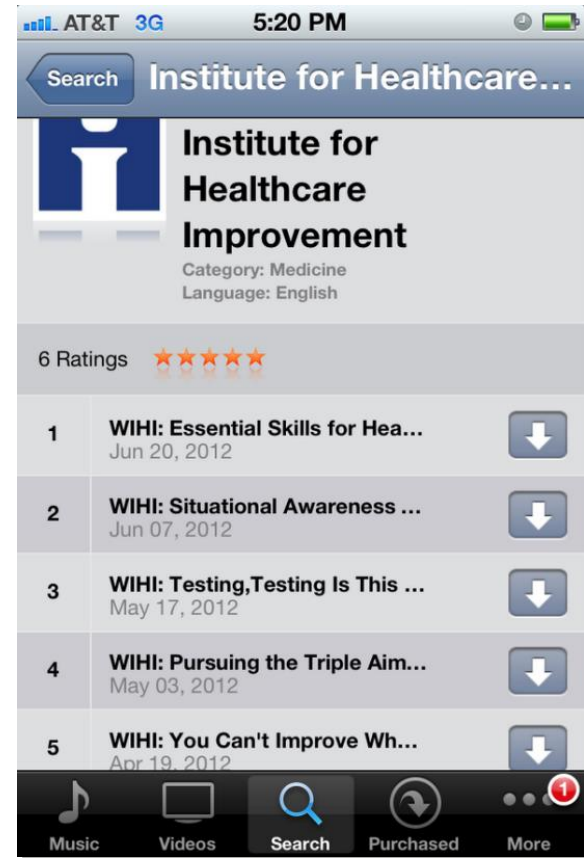
A not-for-profit organization founded in 1991 and based in Cambridge, Massachusetts, the Institute for Healthcare Improvement (IHI) is a reliable source of energy, knowledge, and support for a never-ending campaign to improve health care worldwide. IHI works with health care providers and others to accelerate the measurable and continual progress of health care systems toward safety....

Name	Time	Released	Description	Popularity	Price
1 WIHI: Essential Skills for Healt...	1:02:42	6/20/12	WIHI is an exciting new au...	██████████	FREE
2 WIHI: Situational Awareness a...	1:00:19	6/7/12	WIHI is an exciting new au...	██████████	FREE
3 WIHI: Testing,Testing Is This P...	1:02:06	5/17/12	WIHI is an exciting new au...	██████████	FREE
4 WIHI: Pursuing the Triple Aim ...	1:23:04	5/3/12	WIHI is an exciting new au...	██████████	FREE
5 WIHI: You Cant Improve What ...	1:00:04	4/19/12	WIHI is an exciting new au...	██████████	FREE
6 WIHI: Going, Going, Green Em...	58:59	4/5/12	WIHI is an exciting new au...	██████████	FREE
7 WIHI: What Can You Learn in 9...	58:59	3/22/12	WIHI is an exciting new au...	██████████	FREE
8 WIHI: Highly Reliable Hospital...	59:32	3/8/12	WIHI is an exciting new au...	██████████	FREE
9 WIHI: The Patient Will See You...	1:00:28	2/23/12	WIHI is an exciting new au...	██████████	FREE
10 WIHI: The Social Imperative to ...	58:18	2/9/12	WIHI is an exciting new au...	██████████	FREE
11 WIHI: Have You Had The Conv...	1:02:53	1/26/12	WIHI is an exciting new au...	██████████	FREE
12 WIHI: Removing Barriers to Be...	56:23	1/12/12	WIHI is an exciting new au...	██████████	FREE
13 WIHI: Heard at the Forum New...	56:45	12/15/11	WIHI is an exciting new au...	██████████	FREE
14 WIHI: Night Talks and Nocturni...	57:29	12/1/11	WIHI is an exciting new au...	██████████	FREE
15 WIHI: Health Literacy: New Skil...	57:29	11/17/11	WIHI is an exciting new au...	██████████	FREE

Total: 175 Episodes

Listeners also subscribed to

- New Directions in Health Care



Institute for Healthcare Improvement

Category: Medicine
Language: English

6 Ratings ★★★★★

- WIHI: Essential Skills for Hea...**
Jun 20, 2012
- WIHI: Situational Awareness ...**
Jun 07, 2012
- WIHI: Testing,Testing Is This ...**
May 17, 2012
- WIHI: Pursuing the Triple Aim...**
May 03, 2012
- WIHI: You Can't Improve Wh...**
Apr 19, 2012

Thanks to everyone who makes WIHI possible!



Coming up on WIHI:

- *Engaging and Supporting Family Caregivers*
 - October 20, 2016

- *The System of Safety Health Care Needs*
 - November 3, 2016

