Count Me In
A Patient Perspective On Data Driven Care

Uppsala Health Summit 2018

Marie Ennis-O’Connor
SITGES, BARCELONA
MAY 27-29, 2018
Forget What You Think You Know About Patients
Patient 2.0

“Told I was looking over Thomas Paine’s shoulder”

Elliot M. Stone

“e-patients”

how they can help us heal health care

Tom Ferguson, MD
and the e-Patient Scholars Working Group

@JBBC
So Very Proud of our Dutch Smart House at #HIMSSEurope18 waiting to be dressed up with all kinds of e-health Technology
The Four Stages of Health IT

1. Digitizing the record
2. Connecting all the parts
   a. PCPs to Hospitals, Hospitals to Hospitals, etc.
   b. Third-party apps (decision support, FitBit, digital scales) to enterprise systems
3. Gleaning meaningful insights from the data
4. Converting these insights into action that improves value

Presentation by Bob Wachter MD at HIMSS Europe
We Can’t Wait For Healthcare To Catch Up

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Gilles Frydman, ACOR
How Can We Accelerate Innovation?
Data Hugging Disorder (DHD)

“A significant challenge to progress resides in the barriers and restrictions that derive from the treatment of medical care data as a proprietary commodity by the organisations involved…”

The Institute of Medicine

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The patient is at the very core of every single service they use - they visit their GP, pharmacist, consultant, physio etc - they know everything there is to know about themselves, in the home and outside of it. Yet patient records are not kept with them! mind boggling #irishmed
THE PATIENT IS THE ONLY COMMON DENOMINATOR IN HEALTHCARE

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Ownership vs Access
Data Is Currency
The Guy With The Most Data Wins

Jon Bruner
Data Editor
Forbes

Tim O'Reilly interviewed by Forbes Editor Jon Bruner
5,294 views
Healthcare Is A Data-Driven Industry
Expanding Definition of Patient Data

Clinical Data
Self-Reported Data
Patient Data
Proxy Data
Personal Wellness Data

www.futureofpatientdata.org
Incorporating PROs Into Real-World Practice

MAY 17, 2018

Systems that allow remote monitoring of symptoms in patients undergoing chemotherapy have been shown to help improve patients' quality of life and increase their overall survival (OS). Adoption of these systems has therefore been increasing around the world, but what are the implementation challenges for a clinical oncology practice or health care system? Experts will try to answer this question during "Patient-Reported Outcomes: Expanding From Plenary to Everyday Practice," an Education Session on June 2.

The session title makes reference to an abstract presented during the Plenary Session at last year's Annual Meeting. Ethan M. Bisek, MD, MBi, FASCO, at the University of North Carolina, Chapel Hill, and chair of the June 2 session, presented data from a randomized controlled trial comparing web-based symptom monitoring with patient-reported outcomes (PROs) versus usual care in patients receiving chemotherapy for metastatic solid tumors. He reported that systematic symptom monitoring during outpatient chemotherapy using a web-based PRO system conferred benefits in quality of life, emergency room visits, and OS. Results of the study were published online in the Journal of the American Medical Association simultaneously with his presentation.
We were surprised to find that we could detect specific skin drug reactions in internet health forums six to nine months before any published reports. We were also struck by the detail with which users describe their clinical symptoms. In addition, this pipeline detected a new drug reaction that has not yet been reported in medical literature. This demonstrates the robust potential of internet health forums to provide useful and timely information for doctors and medical researchers.
My patient peers told me:

• This is an uncommon disease – get to a hospital that does a lot of cases.

• There’s no cure, but HDIL-2 sometimes works.
  – When it does, about half the time it’s permanent.
  – The side effects are severe.

• Don’t let them give you anything else first.

• Here are four doctors in your area who do it.
Crowdsourcing: A New Paradigm For Health Research
You can have a direct impact on the future of men with prostate cancer.

The Metastatic Prostate Cancer Project is a nationwide genomic research study for men with advanced or metastatic prostate cancer. We seek to generate the most comprehensive database that will be shared with the entire research community to accelerate discoveries.
When Is A Patient Story More Than A Story?

Corrie Painter, PhD
@corrie_painter

Follows you

Asc Dir @broadinstitute - Angiosarcoma survivor - launcher of cancer thwarting projects MBCproject.org - ASCproject.org - MPCproject.org - Puns

$iamforfries.blogspot.com$

Joined March 2012

7,070 Tweets
1,530 Following
3,195 Followers
10.7K Likes
3 Lists

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Engaging Patients rapidly accelerates the pace of biomedical research

The Angiosarcoma Project slated to launch and enroll patients --
Fall 2016

First data release from the Metastatic Breast Cancer Project --
Winter 2016 / 2017

The next Broad direct-to-patient project launch --
2017

Patients are the biggest stakeholders in our collective efforts to thwart disease.

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We Can’t Wait For Healthcare To Catch Up

Thousands of #metastatic #cancer patients watch each other die on Twitter. We only hope you hear us, and are driven to fund research so that our deaths will not be in vain. Help make my death mean something. Speak up for research #ResearchSavesLives

1:29 PM - 30 May 2018

24 Retweets 73 Likes
Some People Look at Data and See Numbers

Others Look at Numbers and See Faces

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Data With Soul

Maybe stories are just data with a soul.

— Brené Brown —
Fighting Stigma With Story

LIVESTRONG

Fighting Stigma: South Africa

1,586
PUBLIC OPINION SURVEYS

The Anti-Stigma Campaigns were implemented in South Africa and Mexico from 2010 - 2012. They sought to reduce the stigma associated with cancer through culturally relevant and targeted messaging.
“The most exciting innovation of the connected health era is people talking with each other”

Susannah Fox
Ex Chief Technology Officer of the US Department of Health and Human Services
Our Copernican Moment
The Patient Is The Most Under-Utilized Resource In Healthcare

It can be argued that the largest yet most neglected health care resource, worldwide, is the patient...