

SPM Board Meeting May 11th 2010

Conducted via WebEx between 11:30 a.m. to 1:10 p.m. ET
[Click here to listen to the recording \(Appendix A\)](#)

Alan Greene
Carol Peckham
Dave deBronkart
Indu Subaiya
Gilles de Bordeaux
Deb Linton
Jessie Gruman
Paul Wallace
Roni Zeiger
Susannah Fox

Journal Goal: To help PM become a common household, practice and hospital name. We see the journal as a means to instill real meaning into this term. Jessie pointed out the significance of overcoming the infrastructural and financial challenges that have been facing the journal. At times, it's felt like we've been treading water but real progress has been made. We not only have a more established journal infrastructure but we've experienced a "rounding out" of our authorship. Gilles and Sara Green have been essential in establishing the journal's online components and we should expect to see the new website go live in the next few weeks. Alan noted that Rodger Burnnier, a Sr. Researcher at CDC, has agreed to prepare a series of 8 articles for the journal about vaccine controversy and how participation can be the best solution for people to take charge of their health.

- Carol Peckham has joined journal team (great experience from MedScape)
- Kathleen O'Malley is our new managing editor
- Gilles informed us that, in the last few weeks alone, he has received a few articles that would be good for publication

501(c)3 designation received from IRS:

Meredith has already been contacted regarding the transfer.

Membership and Finances:

- 180 Active Individual Members
- 1 Lifetime Member
- 12 Innovator Organizations
- 2 bronze Member org. PatientsLikeMe & Medseek
- 1 Gold - Douglas Drane Family Fund "Boston Foundation" (Danny brought in)

208 members to date total of the above is 196; could someone clarify where the other 12 came from?

- \$43,632 in the bank
- \$60,000 promised by the Mitchell Foundation

This Year's Programs :

The Moment:

Public YouTube channel where people upload self recorded videos depicting the moment they realized they could no longer be passive participants in their care and health. It is to be associated with a public contest. The final goal is to have the best 5-10 submissions reshot professionally for CNN and integrated with Elizabeth Cohen's "Empowered Patients" project. We will be announcing this at Health 2.0 DC on June 7th . We have executive producer Jessy Dillian (producer of "Yes We Can" viral video) working on the project. This project would live, among other spots, on the JoPM platform.

New JoPM Platform:

We've spent a year working with an open source platform for peer review journals called Open Journal Systems (OJS.) The platform was very flexible on the back end but limited what we could do on the front end. As a result we've decided to continue to use OJS for the peer review process but will use a professionally designed WordPress site for our front end. After a peer review has been completed on OJS, it will be manually moved to a new instance on WordPress. The goal is to integrate all of our Internet resources and properties to build a brand for SPM (JoPM, The Moment, e-Patients.net, the Society website) This would also allow for cross platform integration or a single member sign on for all of these sites. Gilles pointed out that the membership software might make single sign on more difficult.

The new integrated sites will look similar to this ePatients screen shot:

<http://design.lionson.com/jpm/eP-home-2.html> (*Appendix B.*)

MedScape:

Carol mentioned the possibility of distributing the journal through the MedScape network. MedScape has a program called the Publisher's Circle where they have license agreements with over 200 journals. Each of these arrangements vary based on what journals want to republish down to the article. MedScape reaches about 500,000 MDs, 800,000 RNs. Because Carol runs the Primary Care page she's in a good position to promote various articles. For example, MedScape ran the launch article of JoPM. Carol expects to see an increase in our MedScape traffic as JoPM becomes more practice oriented.

Susannah Fox on seeing the Journal make a mark: "I have a bias towards action: If we don't have the resources to do something let's cut it off, change direction and move on. But I am very encouraged by what has been said so far."

Infecting society with the meme of PM:

Getting information about SPM into the right blogs and having it represented at important conventions will continue to be important. This is a large marketing and PR challenge that will require the coordination of outreach to both individuals and corporate members.

Danny: The meme and targeting individual members is good but we should try to focus on corporate members

It was suggested that the Patient Centered Medical Home group might be a good audience to target. Many corporate stake holders have similar goals to SPM's.

Getting PM into Med Schools:

Most med schools have not been receptive to interjecting PM into the curriculum beyond a special topics presentation. Danny pointed out that there is simply too much hard medical knowledge to cover and softer subjects will always get pushed to the side.

- Traveling grand rounds presentations might have a promising turn out
- Learning about PM during clinical rotations could also be effective. This would involve connecting the younger generation with people like us as they are learning how to interact with patients.
- We could also create an educational activity on MedScape module whereby clinicians can earn CME credit. This could present an opportunity to bring in John Berci.

Other ideas about the upcoming year:

- Paul Wallace mentioned that employers have a vested interest in keeping their employees healthy and getting them PM. We could pilot programs with various employers and then offer this as a service to members. We would like to develop a business case for this approach.
- SPM could also sponsor an awards dinner honoring individual clinicians
- Alan: Patients are always asking him about ways to find PM practices wonders if there's some way to highlight the best of whats going on.
- The Society could offer resource reviews, identify successes stories or tools / vendors that different implementation groups have used.
- Indu suggested that we offer reviews for individual consumers interested in seeking out PM. She's interested in the development of a single infrastructure to evaluate practices that could support many different front ends. The same rubric could support an SPM employer program or SPM consumer reports.
- SPM could also develop a seal provider program for patients, providers and employers following SPM. With that model, SPM membership would certify an individual or organization as a supporter of PM but those that follow formal PM principals would get additional seal
- Danny: What is our value prop for our corporate members beyond logo?
- We wouldn't want to do an annual conference because there is a danger on losing money on it. Similarly, we wouldn't want to do webinars because Dr.s won't attend.
- At some point, gaining credibility and members starts to work at cross purposes to affecting change
- Currently, we give everything away for free. At some point if we wanted to expand, we may have to re-evaluate this. However, if SPM catches on and people find value in it, we should be able to build interest in our programs while generating funds

- Roni: An SPM badge serves both purposes: Each time someone flashes that badge, it gets the word out and earns us money
- One of the goals this year should be taking care of the members we do have by providing them forums so they can communicate with each other. We also want to reach out to member organizations and ask them what they would like to see from us.
- What's our relation to other organizations that have overlapping missions and are doing similar things to SPM?
- What is our unique value proposition?

Alan points out that we need to focus on only a few projects to really provide the Society traction this year

Quickteams:

(update Aug 2010)

JOPM: Jessie / Charlie / Cheryl / Alan / Kathleen / Dan H.

THE MOMENT: Roni / Cheryl

GUIDELINES and CRITERIA: Indu / Carol / Alan

MEMBER SERVICES: Deb / Cheryl / Dave / Susannah / Roni

INDUSTRY RECRUITMENT, FINANCE AND GOVERNANCE: Paul / David L. /Danny / John

AWARENESS: Dave / Susannah Fox / Jon L.

THE MOMENT:

Roni: It's important that SPM is strongly identified with this as a brand so we don't just look like an afterthought. ACOR will also be associated with The Moment. A name change was suggested due to the popularity of "the moment" in a separate campaign.

GUIDELINES/CRITERIA:

Gilles was concerned that, if this group doesn't work closely with Member Services, there is a risk of developing guidelines that are disconnected from reality. Unless these rules are developed to be functional guidelines we could recreate the ivory tower we're working to tear down. This group should probably have a member from all other groups.

This group will ideally develop robust core principles that will support:

- service for independent members
- criteria to review papers by
- tools for doctors to provide patients and vice versa
- educational models
- defining / differentiating us from other groups

We will need a list of principles that does not require policing

MEMBER SERVICES:

This group aims to generate a member email that introduces the new board and engages members wanting to get involved; open an online member forum that is archived on the SPM site; maintain a calendar of PM events to attend (ideally, this calendar would be open for public contribution like a wiki); and develop a tool kit for those that wish to become ambassadors of SPM in their own communities.

For the time being, Cheryl has offered to continue to plug volunteers into particular tasks from a task list that was generated.

INSTITUTIONAL RECRUITMENT, FINANCE AND GOVERNANCE:

This group is devoted to identifying the needs of corporate members and generating fundamental resources. This group will make the case for corporate members to join and stay involved.

AWARENESS:

PR, e-Patients site, marketing, speaking at meetings, Twitter, FB

Appendix A – Recording of 1:40:26 meeting held on May 11th 2010

<https://ciscosales.webex.com/ciscosales/ldr.php?AT=pb&SP=MC&rID=43684842&rKey=3a3f31700aadb822>

Appendix B – proposed layout for new family look

Feature Joe Kvedar's "cHealth blog" (Connected Health)



3 | retweet | f share | 9 |
Date | Apr 25, 2010
We're long overdue in welcoming Joe Kvedar MD of Partners Healthcare to the blogosphere. From his About page:
"The term "connected health" reflects the range of opportunities for technology-enabled care programs and the potential for new strategies in healthcare delivery.
*A division of Partners HealthCare, the Center for Connected Health works with Harvard Medical School-affiliated.

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Welcome



Participatory Medicine is a cooperative model of health care that encourages and expects active involvement by all connected parties as integral to the full continuum of care.

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Recent Posts

Dennis Quaid's "Chasing Zero"



9 | retweet | f share | 9 |
Date | Apr 25, 2010
Actor Dennis Quaid has produced an outstanding, informative, empowering and motivating CME program, "Chasing Zero: Winning the War on Healthcare Harm." It's on the Discovery Channel. Part 1 is here.

This is the best-produced material I've seen to change how so much of the healthcare industry has its head in the sand about the possibility of change.

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Insights on how the HITECH stimulus plan is working

3 | retweet | f share | 9 |

Date | Apr 22, 2010

In my previous post I noted that Vince Kurlatis and David Kibbe are running an excellent series, "Is HITECH Working?" After a full year of increasing tensions, claims, and counterclaims, reading these posts has given me hope that it's all panned out into something mortals can understand. (I'd been afraid to look)

In a day or two I'll be submitting the next entry in the series, on disruptive innovation - patient driven disruption. It's a wonderful moment in our history when two of the best minds in health IT predict this is what's coming.

But I means we have work to do. So if you're into health IT, please catch up on this series - it's clearly written ...

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Save lives first, "then" compete: Simple Interop for Healthcare

8 | retweet | f share | 9 |

Date | Apr 22, 2010

This post is my own expression, not an official view of the Society for Participatory Medicine.

Vince Kurlatis and David Kibbe are running an excellent series, "Is HITECH Working?" In last week's entry they linked to this side deck by Wes Risher and David McCallie of IT consulting firm Oathier. See discussion before watching.

READ MORE > 17 COMMENTS >

The HealthCare Pyramid - Views from the Apex and the Base

24 | retweet | f share | 9 |

Date | Apr 15, 2010



What we looked in the past about "top-down" - doctors who become a patient's hero/heroine. Our own founder, Tom Ferguson MD was one.

"E-patients" are a special case that grows, one and for all, from being an e-patient has nothing to do with reaching the medical establishment, at some base level, being a patient, or any patient, is about being empowered, engaged, and participatory.

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Found on the Net

"The stage is being set for patient-driven disruption"
Apr 29, 2010
The e-Caremanagement blog has released my post that we mentioned last week ...

Teaching HIPAA with a Seinfeld clip
Apr 24, 2010
On my personal website I posted a HIPAA clarification flyer that I made up. "It's your medical record. You have a right to it. It's the law." The PDF links to a Seinfeld ...

Healthcare's Privacy Problem (Hint: It's Not What You Think It Is)
Mar 25, 2010
Lygela Riccardi's post today on The Health Care Blog begins: I recently applied for life insurance. The broker, whom I've never met, asked about my health history. "So you've just had a baby," he ...

E-Patient Erin Proves a Point
Mar 2, 2010
Erin Turner recently wrote: When I arrived at the Mayo Clinic in Rochester, Minnesota a few weeks ago, I was asked: "Who referred you to us?" My answer was not traditional: "Twitter" ...

Pay me now or pay me later.
Feb 3, 2010
Alfred Sommer's Washington Post column: "Tragedy of individual patients risks overshadowing chronic health problems" gets to the heart of the power of public health, communications, and the personal choices which make a difference ...

Journal of Participatory Medicine cited on Scientific American blog
Dec 11, 2009
Scottish-American writer Robin Lloyd (Twitter: @RobinLloyd99) has written a nice, clear, hit-the-nail-on-the-head post on their blog about our Journal of Participatory Medicine.

Stupid Cancer Show
Dec 10, 2009
Listen in at 9pm Eastern on Monday, 12/14, to The Stupid Cancer Show. Host Matthew Zachary will interview Edward Shin, MD, founder of Healogica, Inc., Jane Sarasua-Harris, a health economist and ...

Limiting Controversy: David Eddy at JGIM
Sep 01, 2009
David Eddy did nothing to reassure Hart Bollen about evidence-based guidelines in his recent keynote, saying as tentatively: "The problem is that we don't know what we are doing" (8)

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White Paper

e-Patients: How They Can Help Us Heal Healthcare
DOWNLOAD THE PDF (678KB)
READ/VIEW THE WIKI VERSION >

"The Moment" Video Series

Voices of Open Access: Sharon Perry, Patient Advocate



Oct 20, 2009
Sharon Perry discusses access barriers in medical devices and how open access is necessary for patients and caregivers to adequately learn about their own devices.

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Quoted

"It might seem obvious but a critical EHR safety issue is making sure that you have correctly identified the patient before you with the records on your screen."

Sherry Reynolds in Panelist questions for ONC's 2/25 hearing on EHR patient safety issues.

MORE IN QUOTES >

Recent Comments

"Gimme my damn data!" The stage is being set to enable patient-driven disruptive innovation.

Why Health Care Professionals Should Practice Participatory Medicine: Perspectives of a Long Time Medical Editor

Participatory Health Care: Perspective from a Nurse Leader

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From the Journal

The Voices of Choking: The women discuss living with choking disease.

Is any Research on Participatory Medicine in pregnancy?

Scarepeak Post on social sharing in online communities

James Reynolds on the A.L.S. community at PatientVoice

Dear Mark, RE on the Green Talk community

Jim McClellan on Oathier's side deck

Navigation menu with categories: HOME, FEATURED STORIES, TOPICS, ABOUT, FEEDBACK, and various sub-topics like Ethics, Found on the net, Patient education, Policy making, etc.