

Minutes of SPM Board Meeting August 30th 2010

Conducted via WebEx, 11:59 a.m. to 12:36 p.m. ET

Meeting number: 203 588 450

<https://cisco.webex.com/ciscosales/lsr.php?AT=pb&SP=MC&rID=45929102&rKey=87b120fdc3bef01b>

Present:

Alan Greene
Cherly Greene
Carol Peckham
Dave deBronkart
Indu Subaiya
Deb Linton
Jessie Gruman
Paul Wallace
Roni Zeiger
Susannah Fox
Danny Sands
John Grohol
Charlie Smith

[00:06:52] Welcome: co-chairs Dave deBronkart and Alan Greene

- Looking back & looking forward; call to action
- Review of Quick Teams

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.

[00:08:58] Approval of Minutes: Jessie moving, Carol seconding – Minutes approved

[00:10:17] Guidelines and Criteria of Participatory Medicine:

<http://www.jopm.org/editorial-policies/#focusAndScope>

- Started with the guidelines and criteria Jessie and Charlie spearheaded
- Defining PM for patients, providers and institutions to provide the following:
 - Check-list for patients helping them know where to start
 - Ground rules for provider and institutions
 - Definition of JOPM scope
 - Research and reviews to decide when individuals or institutions meets this definition
 - Foundation of a Seal Program for individuals or institutions that adopt this criteria
 - Basis for Society membership
- Timeline: Process/draft will be completed in time for Health 2.0 so we can get feedback in San Francisco
 - Final draft early 2011
- Other documents used:
 - Jessie's Patient engagement group
 - AHRQ engagement in the patient home
- Board feedback on Update:
 - **Jessie:** Cautions that people might have a hard time understanding the responsibility her group's document places on patients. Her group is mostly writing from a perspective of patient advocacy. If her document is to be used in this process, it should incorporate more guidelines for what providers and institutions should do. Otherwise, patients may feel like additional responsibility is being dumped on them.
 - **Carol:** We are really trying to develop guidelines aimed at outcomes with evidence to indicate improved patient care
 - **Indu:** We hope to see this spread out into the community - perhaps even crowd sourced approvals and recognition for people that embody PM goals
 - **Roni:** if people agree with PM we should provide them something specific they can do (i.e. put an SPM badge on your website or twitter icon) The small act of doing something explicit could help further commitment
 - **Danny:** Great idea but we should also make sure that the people using our seal are members we can sign up.
 - **Unidentified:** There should be a way to allow non-members to use the badge - it would make it easier for us to find them and to increase our movements momentum
 - **Indu:** Something that was discussed in the smaller group was that there should be ways of capturing various degrees of commitment to the principals we set forth. For example, an individual could be a member and not adhere to SPM principles. Likewise, an institution might not meet all of our criteria but could still make a valuable member if they were working to improve. (also mentioned in May 11th

- meeting minutes)
 - **Dave:** The Society doesn't have the resources to police criteria and this group should work with Member Services to develop policies that are founded in reality (these two points were also mentioned in May 11th meeting minutes)
 - **Dave:** Suggested MPSF Patient Compact as a resource
- **Fundamental questions related to the use of the SPM Seal:**
 - Do you already have to be a member?
 - Do we use the seal as a means of helping PM go viral?
 - Both?
 - Are members committing to having accomplished what we set forth in the guidelines or just moving towards those guidelines?

[00:21:31] Awareness and Outreach – Dave

- **We want people to be aware of:** The Society in general (SPM itself) ; Society online properties (e-patients.net, JoPM, participatorymedicine.org) ; Society memes (participatory medicine, e-patients)
- **Results:** Depicted by Google mentions per-quarter
- **Methods:**
 - The blog: Guest posts and cross-posts are welcome
 - Individuals: Social media traffic
 - Social media: This team is not very active yet- Chai Wu from 23 AND ME has now joined and will be able to help us with social media outreach
 - Public speaking: Listing when and where we'll be speaking and then also where we'll be present
 - Benchmarking current traffic: mainstream media mentions, social media mentions for each property, awareness of Society, "e-patient," "participatory medicine"
- I think it was Deb who suggested this but we would like to create a Wiki calendar - events where SPM board, JoPM Ed board & Adv board, Founders Circle are speaking & attending.
- Susannah pointed out that we should develop a slide share for speakers to use when they want to talk about PM. We should make those slides easily available on our website / slide share account
- Patient Speakers Bureau or SPM Speakers Bureau to provide speakers on request (discussion with Trish Torry)
 - We would need to think more about the parameters/requirements for being listed
 - This should also eventually be made available on our website

Membership and Member Services [00:34:22] – Deb

- We've already looked into developing a calendar of SPM board member speaking engagements.
 - The idea is to help members stay up-to-date on board member activity and capture all the energy that is already going towards the promotion of PM
 - This will be a page added to SPM.org
- One of our goals this year is to develop an easy intake method for volunteers to become involved
 - The more volunteers we can engage the more informed our membership will be
- If you need a volunteer, develop a concrete task description, how that task fits into the a larger SPM objective and include a description of needed or preferred skills
 - Email Cheryl or Deb this Who / What / Why
- **Cheryl:** Currently plugs people in but, until recently, we have not aggressively recruited members as there hasn't been a system in place to absorb them
- To date, we have had 11 volunteers come to us through the website
 - Some are PhDs wanting to help with various projects
- We think we can get many more volunteers if the Quick Teams are ready to make good use of their positive energy
- We'd like to send out a letter out to members and could use your input
 - Please send Deb any points you'd like to communicate to members
- One of the issues we face is continuing to stimulate conversation among our membership
 - It's debatable whether we want to start the list-serve again or if there's a new way to get conversation going via our existing online entities
- We want to make sure that when someone signs up they get welcomed, receive a brief on the journal and e-patients and are then invited to a conversation.
- Member Networking Receptions will be held in the East around the time of The Center for Connected Health Symposium & West around the time of the Health 2.0 Conference.

[00:46:42] Journal – Charlie

- We spent time transitioning from the OJS bare bones sight to being able to launch our own branded journal online.
 - Even though we launched in 2009 we couldn't really say we had a journal online until about the 1st of Aug 2010
 - Sarah as Managing Editor left for a new job
 - Kathleen has been our new Managing Editor for the past couple of weeks but will need some time to transition in
 - Since launch we've been able to publish new articles
 - We hope to encourage submissions and launch new publicity around

mid Sept

- Substantial increase in exposure is needed to attract more readers and editors
- We need to clarify with readers and contributors about where we stand as a journal giving all this transition
- We need to get this indexed in MedLine and PubMed
- We want to start to aggressively encourage content
 - There was a gap but we now have a process
 - Messages about a need for submissions around 15th
 - CDC has already published a set of vaccination articles we could use for the journal
- What is the plan for communicating that the journal is back?
 - Kathleen just tasked with outreach
 - Because we're not indexed, it's hard for scholars to take a chance on us because they need publications for tenure
 - We're also getting a lot of the qualitative work done (websites and resources)
 - We need this board to submit short research and media watch pieces
- Can we provide service guarantees?
 - We need reviewers from this board to make up for a lack of robust reviewers
 - We spend a lot of time pulling teeth trying to get people to follow through on what they agreed to do
 - if you give us a few months to jazz up the board we could offer guarantees
- **[01:02:58] Susannah:** "Not to be the skunk at a party but..." How could we marry the e-patients blog and the Journal site- I have trouble believing we could have an impact unless we get the journal going quickly. Every time I see another mainstream journal post a participatory med study I think, "why do we need our OWN journal? The idea of PM is spreading so fast do we really need our own outfit? "
- **Carol:** the journal can't be developed quickly and it needs time to develop a reputation based on content. I think it as a important unique role. No other journal's role is to consolidate this type of researcher information.
- **Roni:** We should reach out to the authors that have published in these other journals and ask them why they didn't chose to publish with us.
- **Susannah:** It's important that these shorter and quicker pieces are being solicited. Is there a way to yolk the spirt of the journal and the spirit of the blog.
- **Jessie:** Its been hard to get imperial and case studies to compliment our opinion base.
- **Indu:** who is curretting the 5 most important PM articles out there? With the most agnostic approach to who we highlight [1:11:34]
 - Jessie we have a section called the Viewpoint that might be adapted to support such an approach

- **Deb:** The struggle between PM as a concept and PM as formal entity is a recurrent issue. Tweeting news stories might be a lightweight way to bridge that gap. It could allow the formal brand of the Society to be associated with aspects of the larger PM movement.
- **Roni:** We could also develop a shared document reviewing important articles we could update throughout the week and distribute it as a newsletter.

[01:15:05] The Moment – Roni

- Slow progress
- Working with Gille and with Jesse Dylan who produced the Yes We Can Viral Video for the Obama Campaign
- 90sec of Why PM
- the people we spoke to seem to have stage fright
 - To address this problem we want to record our own video encouraging people to submit their stories by explaining how easy it really is to do so
 - Currently scheduling with Jessie's studio who is volunteering space

Industry Recruitment, Finance, and Governance – Danny

- Need Elevator pitch
 - PM is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners. The Society for PM is.....
 - Convene
 - Educate / provide resources
 - Provide a network/forum
 - Generate Ideas
 - But we need to have more than words to offer value
 - What are we? Academic Resource, Convener, Information Resource?
 - How can we offer a value proposition to our corporate members
 - We need people to roll up their sleeves and do the work of putting together forums
 - **Jessie:** We have secret language that we seem to speak amongst ourselves but we haven't been able to translate that for outsiders
 - **Indu:** What was it that brought these corporate members in? Can we come up with a short list of why they joined?
 - **Danny:** The people who joined are not necessarily the people we want to target
 - **Deb:** There are corporate members who might not have the money but could still be valuable by sharing other resources like cross

- publications
- **Indu:** This group shouldn't have to reinvent the wheel; quick teams should send you their content so that corporate members can take advantage of the valuable work that's already being done
- Develop targeted list
- Corporate Member Salon to be hosted on the West Coast
- Consider programs for members
 - Quarterly tech reviews
- Financial Target \$50K for 2011
- Targets for membership
 - Provider Organizations
 - Employers
 - Health plans
 - Consultants that help providers
 - Foundations
 - Advocacy Organizations
 - Union Trusts
 - Application/service/device developers

Election of Officers- Alan

- We want our board members to step up and take more ownership
- No date for Formal Elections Set
- Elections need to be held Annually
- Indu Elected to the Executive Board

Conclusion – Alan