

This document summarizes the Society for Participatory Medicine (SPM) Executive Committee's response to the Development Goals proposal that was developed by the Goals Working Group. Much has changed since the proposal was presented, including much that was a direct result of your work. In many ways, the Goals Proposal document represents an important milestone for the Society, and we will encourage others to follow the strong example you set.

The board was very pleased to see that many of the goals you outlined were aligned with our own, but articulated in a clear and effective manner. Our existing committees (called Quickteams, to encourage nimble action) have already started incorporating some of these suggestions.

To avoid redundancy and to help us make focused progress on the most pressing issues, we want to draw your attention to what we are doing now, where there is overlap with your proposal, and where there are gaps. While we would like to leverage our existing Quickteams, we are also open to the idea of creating new ones. What follows are our recommendations based on your proposals.

Goal A: "Greater clarification/simplification of the mission of the society in ways that will allow people/organizations to understand and value the benefits of membership"

Much of our brand and the core mission of SPM exist on the Society's participatorymedicine.org <u>website</u>. We'd like to incorporate any specific additions to the brand using this page as a springboard for discussion. We agree that we need to define an elevator pitch and to outline our value proposition to different constituencies.

We do not currently have a single committee focusing on this. However, we do have several groups that are stakeholders in this effort:

- 1. The Membership Quickteam
- 2. The Corporate Membership and Fundraising Quickteam
- 3. The Guidelines Quickteam that is developing a clear definition of what it means for patients and institutions to "be Participatory" and how to apply this brand.¹

We agree that a clear value proposition for individual and corporate membership should be identified through a focused discussion with representation from members, SPM leadership, and the groups listed above.

¹ We've distributed the Guidelines working document to the membership listserv since receiving the Development Goals proposal and <u>posted it online</u>. This Quickteam has most recently identified three succinct and actionable items, that are measurable, achievable, and have the power to instigate change. They will keep developing the broader, deeper set of guidelines as a guid to best practices for those interested in going beyond the basics. But you can read the most recent draft of the simplified mission <u>here</u>.



Goal B: "Improvement of communication between the society's leadership and its members"

We agree. There was significant room for improvement in board communications. We have since launched the following new communications outlets:

Members and Community:

<u>Listserv</u> – We continue to foster this very active group discussing a range of topics via email. Discussions are also maintained in publicly accessible and searchable archives for others to learn from. We've also been using this as a quick way to contact our most active members. Please email <u>John Grohol</u> to be added to the list

<u>Paper.li</u> – An auto updating "newspaper" of what SPM members and leaders are saying on their own blogs, twitter accounts and websites.

<u>Twitter</u> – @S4PM highlighting new articles, events and member commentary. There is also the SPM <u>Twitter List</u>, a compilation of our member twitter accounts. We also have hosted our first set of #S4PM <u>Tweetchats</u> where members discuss issues on live twitter chats.

<u>e-Patients.net</u> – This remains the go-to official blog for the society

Board Activity:

The communication of board and SPM's activity has been improved by adding the following information to the Society's website:

- <u>News Section</u> Raw notes and updates from board meetings, Quickteams, and committees
- <u>By Laws</u> How we are structured and the rules by which we operate
- <u>The Speakers Events Page</u> A page containing a calendar of speaking events featuring SPM board members and thought leaders (In search of a new volunteer)

<u>Live Networking Receptions</u> - We've had events on both the East and West coast where members and board members get to connect face-to-face. These meetings have provided the board invaluable feedback and helped us reach more people. Additional receptions are being planned this year. We are also working on a MeetUp template so those in other areas of the country (and world) can host their own gatherings.

<u>Change of board leadership to better engage members</u> – We created two members-at-large positions to work on the Executive Committee and the Board, and we changed the by-laws to permit nominations for officers to come from the general membership.

Member Satisfaction survey – This has not been performed yet for lack of a volunteer.

<u>Newsletter</u> – We are looking to have a concise communication drawn from the News section of the SPM page and summary of member activities on the listserv. This has not been preformed yet for lack of a volunteer.

Although there are many activities already in place to communicate with our members, we admit there is still work to be done. Because there is a great deal of overlap with activities of our Awareness and Outreach Committee, we will task them with the added responsibilities outlined in goal B, however if the situation should warrant it we can create a separate Quickteam with responsibility for internal communication.



Goal C: "Greater public visibility for the society and clear communication of its mission to the media, the professional health care community, and the consumer/patient community"

We are constantly trying to raise awareness about the society so that it is "taken more seriously." *The Journal of Participatory Medicine* (JoPM) is the best example of this as it provides citable resources for those trying to substantiate the importance of Participatory Medicine (PM) in research, policy and quality of care. Although JoPM is already syndicated, including on major physician resources such as Medscape, one of JoPM's main objectives is to get "indexed" in Medline so that it will increase its visibility. Getting JoPM indexed will also increase the legitimacy of the Journal and attract higher caliber submissions.

In addition to generating content, we also aim to influence policy. Through the hard work of David Harlow's Policy Committee, we've been able to submit PCAST Recommendations and respond to a CMS proposed rule. The Society isn't just sitting back and commenting on what government and institutions should do – we're jumping into the process itself.

At one point, SPM had a Speaker Events page where we cataloged all the places SPM was being represented by its board members or being mentioned in presentations (referenced above). The page didn't generate much traffic and required a great deal of time to keep updated. Given what you've suggested we've decided to revive this page and are currently looking for a volunteer to edit it on a regular basis.

If you or others are interested in improving our visibility, we suggest you connect with the Awareness and Outreach Committee, Policy Committee, volunteer to review a journal article or sit in on our next Corporate Membership Committee call. SPM is fortunate in the number of members who also happen to be significant thoughtleaders in the field. They're not always the most active members but they are out in the world carrying the torch of PM in to the offices of CEOs, on to the stage of TED Talks and across the airwaves of NPR. The e-Patients blog captures some of these events already but we'll try to do a better job of highlighting our efforts.

We admit there is still much to accomplish with external communication. Because there is a great deal of overlap with the activities of our Awareness and Outreach Committee, we will task them with the added responsibilities outlined in goal C. We also have members that work with marketing firms, and we are working to engage them in some of this work on a pro bono basis.

We believe the new succinct guidelines¹ will afford opportunities for visibility because they are brief, powerful, hard to argue against – and yet not happening in most doctors' offices across the country.

Goal D and E: "A significant increase in the number of members of the society (including all potential categories of member; to be better defined). A significant increase in the revenue of the society (from membership fees and from other potential sources)"

We'd like to increase our membership and improve the outlined ratios but we haven't had the resources to put forth a formal recruitment effort. As mentioned above, we've been hosting face-to-face networking receptions to which we've encouraged members to bring guests. We also hope to assemble a simple recruitment packet that members can use to reach out to others (we're in search of a volunteer for this project as well).

The majority of our revenue does not come from member dues. We have an extremely liberal scholarship program, very low member rates and rely heavily on corporate member contributions. We have passed along your suggestion about reworking our corporate membership system to the Corporate Membership



Quickteam. We have also been hard at work planning for a series of invited dinners with speakers for our prospective corporate members.

One of our challenges has been the lack of personnel willing to do the solicitations of corporate members. We welcome suggestions on how we might accomplish this in our volunteer organization.

Goal F: "Development of one of more pilot initiatives that would allow SPM to demonstrate how participatory medicine can be to the benefit of all concerned in very practical ways"

Agreed, this has been part of our plan all along. We have one such initiative underway, which is the aforementioned Guidelines Quickteam and the Seal Program which is based on the short-form guidelines. But there are many other ideas that we've thought about, including educational programs, formal certification programs, online educational resources, and others. We don't lack ideas, just the people to help us bring these ideas to life.

We are proposing that members self-organize task forces to propose these projects, ideally using the Vision-Strategy-Execution-Metrics template that your document used. Then the leadership can select projects based on the maturity of the thinking, the resources required, and the people available to execute.

We thank you very much for your thoughtful suggestions and look forward to fruitful dialogue.

Sincerely,

The Society for Participatory Medicine Executive Committee

