

Development of Some Simple, Short-Term Goals for the Society for Participatory Medicine (SPM)

BACKGROUND AND CONTEXT

The SPM has evolved from a group of “advisors” to Tom Ferguson, MD – a pioneering “e-patient” and educator -- into a formal organization with two current, primary activities: the publication of a “professional” journal (the *Journal of Participatory Medicine*) and the blog e-patients.net.

Early in 2011, Society leadership invited the formation of a working group to propose a brief list of key goals for the Society that could be prioritized and that could either be fully accomplished or at least meaningfully initiated within a maximum of 18 months (i.e., by October 1, 2012). The following report is an outline of and rationale for these proposed goals.

In drafting this report, the Working Group wishes to emphasize what they saw as their key remit, which was to identify specific problems and suggest goals that – if achieved – would help to offer solutions to those problems. It was **not** the remit of the Working Group to develop fully fledged solutions. That is a second step.

Here is a list of the issues that we believe are priorities:

- We need to grow awareness of and membership in the Society if it is to be “taken seriously” by the professional health care community, as well as by the various sections of the patient, e-patient, advocacy, and commercial communities that have a strong interest in the broad application of collaborative/participatory, patient-centric health care.
- The Society will need significant revenue to accomplish its mission.
- The actual mission of the Society (as opposed to its general premises and principles) is difficult for the “uninitiated” to grasp. Even among its members there is significant variation in understanding about what the Society stands for. Among those who we would like to influence and those we would like to become members, there is even less clarity about whom and what the Society represents, or why they should become members.
- The “structure” of the society is poorly defined for members, and communication between the leadership and its members **about the activities of the society** is irregular at best.
- Awareness of the actual activities of the society among its members is minimal by comparison with awareness of the activities of individual members of the leadership.

The following is a list of six goals proposed by the Working Group. In the remainder of this document we have provided specific details regarding the need for, vision, strategy, execution and metrics related to the accomplishment of each of the six goals proposed:

LIST OF GOALS

- 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 (“**Why should I care?**”)*
- B. *Improvement of communication between the society’s leadership and its members (“**What is the Society actually doing?**”)*
- 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 (“**Who does the Society speak for?**”)*
- D. *A significant increase in the number of members of the society (including all potential categories of member; to be better defined)*
- E. *A significant increase in the revenue of the society (from membership fees and from other potential sources)*
- 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 (“**How does the Society make a difference?**”)*

ADDITIONAL COMMENTARY

In identifying the goals outlined above, the Work Group wished to be very clear that these are not, by any manner of means, the only priorities we see as needing careful and (relatively) immediate attention.

Just as examples, we offer the following additional observations:

- SPM needs to review its goals on an annual basis and ensure that there is a continuous improvement process built in to the goal-setting/review process.
- SPM needs to compile data from research that clearly demonstrate the benefits of participatory medicine in improving patient outcomes.
- SPM needs to explore collaborations with other organizations that are conducting research on participatory medicine.
- SPM needs to engage with its own members on developing and defining research initiatives focused on participatory medicine.
- SPM needs to identify, document, compile, and publish data on gaps and barriers to adoption of participatory medicine based on literature/external assessment and membership feedback.

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*

Statement of need: The core mission of the SPM is difficult for its members to articulate to others and does not offer a simple and emotionally compelling reason for people/organizations to join SPM.

Vision: Participatory medicine is at the core of future, health-related data and information interchange – between patients/consumers themselves and between patients/consumers and the professional healthcare community. But ... ***The SPM needs to be able to tell people what the society is about and why we matter.*** This is the beginning of building a “brand.”

Strategy: Form a working group tasked with development of not more than three or four very simple and emotionally powerful “core” messages about what the SPM stands for and why differing types of individuals and organizations will benefit from membership. These messages will serve as the value proposition for SPM and will need to be based upon the benefits participatory medicine has demonstrated in health care (e.g., research, literature)

Execution

- The working group needs to include:
 - Appropriate representatives from the SPM’s leadership team
 - At least a couple of experienced health care marketing communications professionals
 - A diverse set of other members of the SPM
- It is critical to remember that this process IS – absolutely -- about “promotion” of the features and benefits of membership in the society to a highly definable set of target audiences.

Metrics

- Development and approval of messages by SPM leadership by July 1, 2011
- Involvement of an appropriate “range” of member types in the workgroup
- Actual uptake, consistent use, measurement of the use of these messages by individual leaders of the society in writing about, conversations with and presentations to others, and by individual members
- Uptake and use of these messages by third parties in talking/writing about the society
- The ability to clearly associate the use of these messages with an ROI in terms of recruitment of new members, the generation of revenue, and the achievement of other highly defined goals

GOAL B

- *Improvement of communication between the society's leadership and its members*

Statement of need: SPM's members (a) want SPM to model the accessibility and transparency in its operations that it seeks for health care **and** (b) are looking for leadership and guidance about the true mission and tactical opportunities that will help individual members to see the SPM as a critical component of the evolving healthcare system (at least in the USA)

Vision: The membership of the society should receive regular, simple, and straightforward communications from the Society's leadership about all aspects of the operations and activities of the society that build a sense of a community with a strong focus and a collaborative mindset about improving the quality of information and care needed by every individual patient.

Strategy: Build a small **internal** communications team that can put together and execute a clear plan and tactical methods to ensure that members feel a real sense of value from belonging to SPM and provide feedback to the leadership about whether the society is identifying and meeting appropriate objectives.

Execution:

- Conduct a complete audit of the SPMs current communication methods to members.
- Develop mechanisms for *participatory design* for the operation of the Society (including feedback from members as to type[s] of communication they are seeking from leadership)
- Clearly communicate what SPM's leadership is trying to accomplish for its members (as confirmation for people of why they need to belong to the society)
- At least record and provide summaries of all Board meetings (technology/process implemented by May, 2011)
- Produce and disseminate summaries of all Board committee meetings within 7 days (and measure number of meetings with summaries produced/disseminated within this time frame)
- Provide brief quarterly updates on status of all SPM goals (4/4 quarters in 2011 with goals and updates published)
- Develop open process for nominations/elections of officers and Board members

Other possible measures of success

- Understanding of roles of Board members/other "leadership level" members
- Early participation by new members in SPM-specific activities
- Member satisfaction "minisurveys" (on SPM web site?)

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*

Statement of need: SPM **must** (a) be seen to be thinking and acting on behalf of its members in ways that will compel others to join or collaborate with the SPM and advocating for the value of participatory medicine in improving patient outcomes across health care sectors **and** (b) establish itself as a peer to other influential societies (patient organizations, medical societies) to learn, share, collaborate, and magnify its impact

Vision: The SPM must have a high degree of relevance and significance to the future of health care. We must make it very clear **why SPM is important** and **what SPM is seeking on behalf of its membership**. The average journalist, politician, or a hospital CEO hasn't yet heard of SPM at all. That needs to change.

Strategy: SPM needs an external communications plan to **raise its stature** in the worlds of medicine, public health, and health care as a service industry that operates with the good of the patient as its fundamental priority. Its members need the SPM to **become really important! People need to care what the SPM thinks** about carefully defined issues.

Execution: The SPM doesn't have millions of dollars to spend on PR and advertising. However, there are substantial research data that can be leveraged to transform legacy mindsets about the benefits of participatory medicine. We need to identify and apply striking and easily understood examples of things that are important to the membership and where specific types of change can resolve important problems over time. The SPM also needs a spokesperson who can speak to the media. The media need "a source" to whom they can come for guidance and to understand the SPM's position on key issues.

Metrics:

- Mission, values, and operating principles available to all members as a messaging document for repurposing in their work, by July 1, 2011 (see Goal A above)
- Media mentions, measured monthly and trended, beginning May, 2011; specific goals to be identified compared to current mentions
- Speaker tracking system, operational by June, 2011, 10 external speaking appearances by individuals representing themselves as SPM, by end of 2011
- Specific invitations to leadership team to "represent" the SPM at appropriate forums

- “Outgoing” placements of articles/commentaries written by members about the society and what it does.

GOALS 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)*

Statement of Need: The stature/power of SPM — as with any other society — is critically dependent on the size and authority of its membership. Furthermore, the current ability of the SPM to take action on a wide range of potentially important issues is seriously constrained by its financial resources.

Vision: Any individual or organization with any interest whatsoever in the concept of participatory medicine should become (or at least seriously think about becoming) a member of SPM, and the society must be able and willing to appropriately represent the well-defined shared interests of this group of individuals and organizations.

Strategy: A membership development work group needs to be formed and tasked with a series of very specific objectives. At a minimum, this set of objectives should include the following:

- Define an acceptable total number of members that we are sure can be achieved (a) by December 31, 2011 and (b) by December 31, 2012, with “stretch goals” for these dates¹
- Define a series of **categories of individual membership** – all of which have equal rights as defined by the society’s bylaws, but which help us to ensure a well-balanced membership over time.
- Re-think the categories of organizational membership (because the only one that seems to be working is the innovator organization membership)
- Define an acceptable target individual membership ratio that is in line with the mission of the organization (e.g., 30% patients/consumers/caregivers, 30% practicing physicians and other health care providers; 20% researchers; 10% health care administrators; 10% others)
- Development and implementation of a tactical plan to accomplish these membership goals in the short- and longer-term.

In addition, a business development team and a Board committee to which that team reports need to be charged (at a minimum) with the following objectives:

¹ The current membership of the society is believed to be < 200. For comparative reference purposes, when it was founded in 1964 the American Society of Clinical Oncology had seven members; 70 people attended its first annual meeting in 1965. As of January 2011, the total membership of ASCO is > 29,000, and > 25,000 people from all over the world will attend its annual meeting in Chicago this year.

- The development of a structured business development plan for the second half of 2011 and the whole of 2012 (to be in place by no later than July 1, 2011 and December 31, 2011, respectively)
- Very specific financial goals related to income from membership, events (an annual meeting of the SPM?), funding from commercial sources, and funding for well-defined projects from grants
- Understand how sources of funding impact the mission and participation of organizations, i.e. for-profit, non-profit, grants, commercial interests, and develop transparent policies and processes regarding funding of SPM that are evident to all and consistently applied.
- A clear methodology for addressing issues of financial transparency and conflicts of interest related to sources of revenue
- The willingness to actually bring in revenue on behalf of the SPM. (This is not an academic exercise)

It should be pointed out, however, that there are companies to which some of these activities can be outsourced.

Execution: Methods of execution to achieve these two goals will need to depend on the strategy the talents of the membership development work group, but every single members of SMP should be encouraged to enroll at least two more individual members.

However, this is **not** an academic exercise. The business development team needs to have a “for income” mindset within a “not-for-profit” environment. Before we can put together a business development plan for the SPM, there will need to be a very clear understanding on the part of the business development team of what financial commitments already exist and what sorts of activities the membership is actually willing to support.

Measures of success:

- Involvement of current members of SPM at every level in the execution of the tactical plan.
- At least 300 members of SPM by December 31, 2011
- Success in achieving public recognition about the growth of the society (see Goal C above).
- Continuing success in maintaining/increasing the diversity of the membership
- Achievement of revenue goals defined by the business development team by December 31, 2012

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*

Statement of need

- Actions speak louder than words. SPM needs to DO things that its members can recognize as beneficial to them as individuals or to the communities they represent.

Vision: There is nothing like a series of successful pilot initiatives to show people what is possible, and there are other organizations that the SPM can and should consider working with to develop and execute such pilot initiatives. Such pilot initiatives should very clearly be designed to demonstrate how participatory medicine could and should work in a real-world

Strategy: A work group should identify a small set of potential initiatives and partners with which SPM could collaborate to execute each initiative; meetings would be necessary to explore these possibilities. Ideally, the SPM should have at least two well-defined pilot initiatives in place by July 31, 2012 and to have started to seek funding to initiate the programs.

Execution: Pilot initiatives should meet very clear criteria for timing, output, and “ownership” of any commercializable rights. They should also be very clearly “participatory” in nature, in the sense that they fit well with the mission of SPM.

The Working Group is aware that there is an SPM guidelines committee in place, but the remit and activities of this committee are not entirely clear. We suggest the development and dissemination of a series of materials that describe and define aspects of participatory medicine through accessible, on-line PDFs, web pages, videos and similar materials.

Other organizations with which we might collaborate on pilot projects include: National Organization for Rare Disorders (NORD); Robert Wood Johnson Foundation (RWJF); and Consumer Reports Health.

Measures of success:

- Identification, funding, and initiation of specific pilot project(s)
- Participation of SPM members in conduct of pilot projects
- Ramp up of pilot projects to full scale initiatives
- Recognition of value of pilot project(s) and media reports around execution of the project(s)
- Expansion in membership of SPM related to pilot project(s)



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