



MINUTES

PATIENT ENGAGEMENT TASK FORCE

Date: March 11, 2025 | Time: 7am EST

Hyatt Regency Long Beach, 200 S Pine Ave, Long Beach, CA 90802, USA

Regency Ballroom D

Co-Chairs: Patricia Sylla, MD & Caitlin Halbert, DO

Committee Staff: Loren Hamilton

Meeting Participants: Caitlin Halbert; Patricia Sylla; Mercedeh Baghai; Marylise Boutros; Annie Ehlers; Sierra Grasso; Erin Gilbert; Ryan Howard; Deborah Keller; Leena Khaitan; Kellie McFarlin; John Romanelli; and Bethany Slater

I. Call to Order and Introductions

Dr. Halbert welcomed the task force and reminded attendees of the importance of the SAGES Foundation and Giving Plus Campaigns, highlighting the foundation's long-term support for initiatives. Participants were encouraged to donate, particularly for the 2025 campaign. The code of conduct and the role of society leaders as models were also reviewed.

II. Approve Prior Meeting Minutes – A motion to approve the minutes was made and passed by general consent.

III. Master SOP Review

The SOP was discussed and everyone who participated in the development of the document was thanked. It was shared that the finalized version of the Standard Operating Procedure (SOP) had been supported by the board, with additional discussion on the need to justify patient partner compensation. It was confirmed that Version 6 of the SOP was available on Google Drive.

IV. Patient Partner Network (PPN)

Patient Partner Network Application:

<https://www.sages.org/patient-partner-network-application/>

The PPN and its soft launch were discussed in detail, focusing on patient intake, feedback mechanisms, and form issues, such as unlimited phone number entries and missing email domain requirements. The PPN was made available on the SAGES app, with encouragement to share the link for patient engagement. Several task force members submitted entries through the link provided, which were received. They also confirmed that they received an automated confirmation of receipt of their submission.

The importance of timely interactions and a structured engagement framework was stressed. Quarterly meetings with patients were proposed to maintain engagement and serve as a platform for project discussions. The conversation also touched on the need for a systematic patient engagement approach.

For marketing and recruitment strategies, leveraging Facebook groups, QR codes in patient brochures, and targeted membership messages were proposed. A colorectal cancer awareness campaign was highlighted as an example of a specific patient recruitment effort. The team planned to develop a marketing strategy in collaboration with Julie.



MINUTES

PATIENT ENGAGEMENT TASK FORCE

Date: March 11, 2025 | Time: 7am EST

Hyatt Regency Long Beach, 200 S Pine Ave, Long Beach, CA 90802, USA
Regency Ballroom D

It was requested that a QR code be created by the end of March. It was also suggested that SCOPE be utilized for promotion, with the potential inclusion of branded merchandise. Sending a token of appreciation to patient participants was discussed.

Patient Partner Network Access Request:

<https://www.sages.org/patient-partner-network-access-requests/>

The link was reviewed by the task force, and its purpose was discussed. It was suggested that an option be added for participants to consent to being searchable within the SAGES network. Adding a data privacy statement was agreed upon. An annual re-engagement invitation was also suggested, along with an opt-out option at any time. The honorarium question should be revised to clarify whether organizations will provide funds rather than implying that they may seek PETF funding.

It was requested that the PPN landing pages be categorized under both, **Patients** and **Members**

V. Patient-Reported Outcome Measures (PROMS) Subcommittee Update

Dr. Sylla reviewed the slides that were presented at the recent PROMS subcommittee meeting. Committees were encouraged to pilot the initiative by focusing on one disease entity. Reference materials from the FDA and NIH were suggested for guidance, alongside systematic reviews and direct patient feedback.

VI. SERF Grant

The SERF Grant proposal was accepted to support the work of PROMS. Updates on the SERF Grant and the need for sustained patient involvement, particularly in relation to potential PCORI grants, were discussed. There was further discussion on utilizing patient-reported data for PROM selection and developing a standardized toolkit to aid committees in assessment.

VII. Patient Speaker Sessions at Annual Meeting

Up to five patient speakers will be participating in this year's meeting. Jason will be asked to promote these sessions on the app to encourage greater participation in future years.

The patient speaker sessions at the annual meeting were reviewed, with recognition of existing challenges in finding speakers for certain conditions like Achalasia. Identifying online communities and networks was proposed as a strategy to recruit speakers, with additional efforts to promote sessions through the SAGES app.

VIII. Patient Advocacy Group Outreach **Dr. Grasso**

There was discussion about outreach to advocacy groups, with a list of 50 potential organizations assessed based on factors such as funding, size, and patient-to-patient support. While smaller groups were seen as an accessible entry point, partnerships with larger



MINUTES

PATIENT ENGAGEMENT TASK FORCE

Date: March 11, 2025 | Time: 7am EST

Hyatt Regency Long Beach, 200 S Pine Ave, Long Beach, CA 90802, USA
Regency Ballroom D

organizations were also deemed valuable for credibility and reach.

In the patient group engagement and resource-sharing discussion, leveraging existing networks was suggested to connect with relevant groups and streamline their incorporation into the PPN. The need for a comprehensive list of groups was acknowledged, as well as the untapped potential of closed Facebook groups.

The use of social media and keyword strategies was explored as a method for patient engagement. Using keywords to enhance patient discoverability in relevant groups was recommended. However, concerns were raised about the impact of paid advertising on search rankings. A subcommittee was proposed to oversee patient outreach and advocacy group screening.

Addressing challenges in patient recruitment, distinctions between advocacy and support groups were emphasized. A subgroup was suggested to screen and vet patient communities to ensure alignment with committee goals. Strategies such as Meetup.com were proposed as additional networking and recruitment tools.

For local recruitment strategies, early coordination with Carrie was emphasized as essential for engaging smaller patient groups. Implementation of previously discussed strategies was reaffirmed, with a goal of compiling a list of potential session participants. Concerns about Facebook advertising and the need for consistent content updates were also noted.

IX. Patient input in Education Brochures- Update from Communications

No updates from Communications were available.

X. DLPD & AOSA LGBT Educational Series proposal

The task force was asked to review the proposal from the DLPD group, which was shared within the committee packet, for discussion at a later date.

XI. New Business

With the expectation of increased workload on the horizon, the task force concluded that more frequent meetings will be necessary. Beginning in May, the task force will meet every other month to ensure continued progress on key initiatives.



MINUTES

PATIENT ENGAGEMENT TASK FORCE

Date: March 11, 2025 | Time: 7am EST

Hyatt Regency Long Beach, 200 S Pine Ave, Long Beach, CA 90802, USA

Regency Ballroom D

XII. Next Steps

1. **Patient Partner Network (PPN) Updates (Loren)**

- Add a data privacy statement to the PPN form.
- Create a QR code for the PPN by the end of March.
- Ensure PPN landing pages are categorized under "Patients" and "Members" on the SAGES website.
- Adjust honorarium questions to clarify if external funding will be provided rather than implying PETF funding.
- Add an annual reengagement invitation and an opt-out option for patient participants.
- Explore using SCOPE for PPN promotion.

2. **Patient Engagement & Advocacy**

- Form a subcommittee to oversee patient outreach and advocacy group screening.
- Identify and engage one disease area per committee for the PROMs project and begin building a patient network.
- Work with Carrie on local recruitment strategies for patient engagement.
- Explore Meetup.com as a tool for patient networking and recruitment.
- Coordinate with the Program Committee to integrate more patient speakers into annual meeting sessions.

3. **Patient-Reported Outcome Measures (PROMs) & Research Initiatives**

- Reach out to Dr. Julio Fiore to provide a webinar/training on evaluating PROMs for committee members.
- Conduct a systematic review of validated PROMs and collect patient feedback.
- Develop a toolkit to guide committees in PROM selection and assessment.

4. **Marketing & Communications**

- Work with Julie and the team to create a marketing strategy for PPN recruitment.
- Promote patient speaker sessions through the SAGES app and other channels.
- Utilize Facebook groups and keyword strategies for outreach while assessing the impact of paid advertising.

5. Task force, review the **DLPD & AOSA LGBTQ** Educational Series proposal to discuss at a future meeting.

6. Increase meeting frequency to every other month starting in May.