SAGES Patient Engagement Standard Operating Procedure

Patient Engagement Task Force (PETF)

Last Review Date: November 17, 2024
Date of Origin: October 11, 2024

Definitions

P/PP/PA/PAG: Patient/Patient Partner/Patient Ally/Patient Advocacy Group
DEI: diversity, equity, and inclusion
PROMS: patient-reported outcomes measures
PREMS: patient-reported experience measures
PETF: Patient Experience Taskforce
PPN: Patient Partner Network

Policy

To support the framework for SAGES to partner with patients and align with patient priorities to improve patient-centered care.

Purpose

To build relationships with patients, patient allies, and patient advocacy groups to enhance and expand the work of SAGES. To create a framework with which the SAGES organization and its committees will engage with P/PP/PA/PAG. To position SAGES to be the trusted source for patient engagement in the field of surgery.

Governance

I. Patient Engagement Task Force

   a. Will lead recruitment, maintenance and serve as the interface between the PPN and SAGES committees seeking to engage patients in SAGES committee-related activities. This task force will either evolve into a Patient Engagement Committee or be absorbed by a predetermined SAGES committee.
   b. Members: The PETF includes members representing all SAGES clinical committees, other committee members (research, communications, etc), and patients.

c. Responsibilities:
    i. Review patient applications to join the PPN
    ii. Review requests to access the PPN by SAGES committees
    iii. Educate prospective members of the SAGES PPN regarding SAGES (mission, goals, values, organizational structure), the range of anticipated contributions to SAGES committees, code of conduct, and obtain informed consent to actively participate in SAGES activities.
    iv. Interface with members of the patient partner network (PPN) and serve as point of contact re questions, requests, grievances, etc.
    v. Ensure adherence to the patient engagement code of conduct.
    vi. Remove any patients or SAGES members who are not in compliance with the code of conduct and notify the SAGES leadership

II. SAGES Patient Partner Network (SAGES PPN)

a. The SAGES PPN is a network of patients, patient allies, and patient advocates, who actively contribute to various SAGES projects, initiatives, and activities to align with patient priorities and improve patient-centered care.
b. The PETF is committed to fostering an inclusive environment and encouraging participation from individuals of all backgrounds. The PPN welcomes a diverse group of participants, including those from different cultures, countries, ethnicities, genders, abilities, and experiences, to contribute to and enrich our organization.
c. Application
    i. Patients interested in becoming a member of the PPN must submit an application on the SAGES website (will add link)
    ii. SAGES members, active PPN members, patient advocacy groups, and others may encourage patients to apply to the PPN through application or referral to the SAGES administrator assisting the PETF
d. The PPN participants will be invited to potentially take part in a variety of SAGES projects, including but not limited to patient and surgical education, grants and research, creating and amending guidelines, and the annual meeting and other speaking opportunities.
e. Patients will be asked to provide feedback on their experience after every engagement is complete.

III. Patient Engagement Code of Conduct

a. Participants will engage in a welcoming and supportive environment.
b. Participants will exhibit respect allowing for authentic and expressive discussions.
c. Self-promotion, spam, hate speech, and targeted attacks are not permitted.
d. Participants may have access to confidential and sensitive information, including, but not limited to, information subject to HIPAA guidelines, personal

information, organizational data, and proprietary materials. By volunteering to participate, participants agree to maintain the confidentiality of all such information, both during and after participation. In appropriate situations, participants may be required to sign a nondisclosure agreement (NDA), which legally binds them to protect the confidentiality of the information shared.

e. Any breach of this agreement or the code of conduct may result in immediate termination of the participant's eligibility to engage in current and future projects, and may also lead to legal action to address the violation with and seek injunctive relief and damages being sought against the participant who committed the breach.

IV. Patient Engagement Compensation

a. Participation by patients, patient allies, and patient advocates will often be episodic and limited in scope, time, and effort, since this activity is considered volunteer. However, some projects might require more sustained and effort-intensive contributions (eg. guidelines and grant review, focus groups, co-design or editing of educational materials, etc). Patient partners are considered part-time consultants to the SAGES organization and as such will be appropriately compensated when their level of involvement meets a given threshold.

b. A recommended "financial incentive plan" based on time effort will be developed by the PETF. Engagement in activity(ies) anticipated to exceed a minimum time commitment will be offered compensation based on a sliding scale.

V. SAGES PPN Requests

a. PPN requests are limited to members of the SAGES Committees and Task forces
   i. Consideration for expanded use in the future will be at the discretion of the SAGES leadership.

b. SAGES committee members who are interested in inviting PPN participants for a project will submit a "PPN Request" through the SAGES website (add link)

c. PPN Requests may include:
   i. A patient-perspective needs assessment for a new project or idea.
   ii. Patient engagement in a new or established project.
   iii. Patient speakers for the Annual Meeting or other speaking opportunities
   iv. Examples of support: materials (guidelines, publications, education brochures, etc) creation and/or review, focus groups, research co-author.

d. Requests must include a project description, number of patients requested, area of experience requested, anticipated duration of the project, anticipated time/effort per patient per project, anticipated type of patient contribution (review of materials, serve on guideline or review panel, feedback on project, input on initiative, programing, educational session etc), and a plan for ensuring diversity of patients.

e. The PETF will review committee requests and prioritize to avoid duplication, overlap, or excessive demand on individual patients.
f. The PETF will provide recommendations for financial compensation through use of the “financial incentive plan” as outlined in Section V.

VI. SAGES Committee Patient Engagement Guidance

a. The PETF recommends incorporation of patient-centered language in all appropriate committee goals.
b. Disease-Specific Committees
    i. Patients may participate in the creation of surgeon or patient educational materials, provide on the development of new projects, and other projects as deemed appropriate by the disease-specific committees.
c. Guidelines Committee
    i. Patients are required to participate in key steps of the development of guidelines as outlined in the Guidelines Patient Engagement SOP.
d. Communications Committee
    1. Patients are required to participate in a needs assessment or support development of any new or revised/updated patient education materials.

VII. SAGES Research Engagement Guidance

a. Patients may participate in research project development, grant review, etc. Patients may also participate as a co-author in research opportunities.

VIII. Annual Meeting Engagement

a. Level of Engagement
    i. Program committee/program chairs to request inclusion of patient speakers in clinical sessions from all specialties (foregut, bariatric, hernia, colorectal, HPB, endoscopy, acute care surgery, etc) as deemed appropriate by the program chairs.
    ii. Session chairs should consider opportunities to include patient speakers as deemed appropriate. We recommend program chairs flag sessions that will be expected to include patient speakers.
    iii. Speakers can be invited through use of the Patient Partner Network or direct invitation from their SAGES member surgeon.
    iv. Session chairs responsibilities:
        1. Direct communication with the patient speaker for proper orientation and preparation for their presentation

        2. Recommend providing specific versus vague, open-ended direction
        3. Offer the patient speaker the opportunity to do a practice run ahead of the meeting
  b. Accommodation
      i. Consideration for medical, accessibility, and financial assistance with travel and lodging arrangements for patient speakers is necessary.
      ii. Preference for patient speakers who are local to the meeting location should be considered.
      iii. Patient speakers will require an escort on the day of their session to assist with slide uploads and session room identification.
      iv. Video recording or live streaming presentations should be considered for patient speakers, especially those who are located outside of the meeting location.
  c. Co-design
      i. Patient focus groups should be considered in the early stages of program planning to enhance program design.

IX. Board Engagement

  a. Pending future discussion

X. References

Utengen A, Rouholiman D, Gamble JG, Grajales FJ III, Pradhan N, Staley AC, Bernstein L, Young SD, Clauson KA, Chu LF. Patient Participation at Health Care Conferences: Engaged Patients Increase Information Flow, Expand Propagation, and Deepen Engagement in the Conversation of Tweets Compared to Physicians or Researchers. J Med Internet Res. 2017 Aug 17;19(8):e280. doi: 10.2196/jmir.8049. PMID: 28818821; PMCID: PMC5579322. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5579322/

Chu LF, Utengen A, Kadry B, Kucharski SE, Campos H, Crockett J, Dawson N, Clauson KA. "Nothing about us without us"-patient partnership in medical conferences. *BMJ.* 2016 Sep 14;354:i3883. https://www.bmj.com/content/354/bmj.i3883.long

Wicks P. *The BMJ.* 2015. May 01, [2017-03-28]. Making sure conferences are "Patients Included" https://blogs.bmj.com/bmj/2015/05/01/paul-wicks-making-sure-conferences-are-patients-included/

Payment guidance for researchers and professionals | NIHR

NIHR public contributor payment policy | NIHR

XI. Addendum (websites in beta)

Patient Partner Network Application:

https://www.sages.org/patient-partner-network-application/
password: patientsrule

Code of Conduct from PPN Application:

By submitting your application, you agree to follow the Code of Conduct which includes the following:

Participants will engage in a welcoming and supportive environment.

Self-promotion and spam are not permitted.

Participants will respect everyone's privacy allowing for authentic and expressive discussions.

Participants might come across private information, like personal details, company data, and unique materials. By agreeing to take part, they promise to keep this information confidential, both while they're involved and afterward.

Patient Partner Network Access Request (Needs Assessment, Project Support and Patient Speaker Requests):

https://www.sages.org/patient-partner-network-access-requests/
Password: patientsrule