

Precision Health Participant Advisory Board (PHPAB)

Operating Guidelines

Last Updated July 26, 2017

I. Purpose

The Precision Health Participant Advisory Board (PHPAB) will assist with the design and implementation of research plans for various precision health projects at Geisinger, including the MyCode® Community Health Initiative.

The PHPAB will: (1) develop participant-centered approaches to ensure effective communication between researchers and participants; (2) work to ensure that the needs, interests, and priorities of patient-participants are considered in program decisions; and (3) advance the vision of patient/participant-engaged research as an equitable partnership in which researchers and participants share in the discoveries, benefits, and burdens together.

II. Board Responsibilities

- a. This PHPAB will contribute to precision health projects at Geisinger by considering issues, reviewing plans, and making recommendations to the Principal Investigators of the various precision health projects.
- b. Board members will share ideas and provide meaningful input and ongoing feedback on specific research policies, protocols, and priorities for the various precision health projects.
- c. PHPAB members may help
 - i. prepare and refine educational resources for MyCode;
 - ii. develop research recruitment, engagement, and retention strategies;
 - iii. determine areas of priority (diseases/conditions, health outcomes, topics) for study within MyCode and precision health projects; and
 - iv. improve the research experience for participants.
- d. Members are expected to
 - i. attend quarterly meetings, as well as other ad hoc meetings occasioned by special circumstances
 - ii. contribute to tasks
 - iii. respond promptly to communications
 - iv. keep business information confidential
 - v. manage or eliminate any conflicts of interest
 - vi. comply with the Geisinger Code of Conduct and any applicable laws, regulations, and policies

III. Board Composition

- a. The Board shall be composed of no less than three (3) and no more than seven (7) individuals.
- b. The Board shall be led by two Co-Chairs.
 - i. The first Co-Chair must be a Geisinger research faculty facilitator who must also be a research faculty member and a member of the Patient Engagement Working Group.
 - ii. The second Co-Chair must be a patient-participant member. The term for this office is one year, and there is a two term limit for this office. The first organizational meeting of this PHPAB will include nominations and election of this Co-Chair by majority vote of the members.
 - iii. The Co-Chairs are responsible for setting the meeting agendas; running the meetings; keeping notes of meetings; selecting, welcoming, and onboarding new members; and reporting to leadership.

IV. Board Member Selection Process

- a. Eligibility. Any individual who is a Geisinger patient or is a participant of the MyCode® Community Health Initiative.
- b. Selection.
 - i. Candidates will be considered on an ongoing basis.
 - ii. Interested individuals may contact the first Co-Chair (or a contact person who may be designated from time to time for this purpose) to express their interest. Additionally, Geisinger employees may nominate individuals.

- iii. The initial PHPAB will be selected by the first Co-Chair (described in III.b.i above) and invited to serve. Vacancies will be filled by the two Co-Chairs after reviewing applications and interviewing potential members.
- iv. Selection criteria. Diverse perspectives are essential to the PHPAB. Individuals should have a strong interest in helping to improve Geisinger practices and policies for research, including specifically an interest in helping to strengthen Geisinger's biobanking, genomics, or big data research.
- c. Onboarding Requirements. Individuals who accept an invitation to serve on the PHPAB must complete the onboarding requirements before serving on the board. This includes any necessary training, screening, or conflicts of interest reporting that may be specified from time to time.
- d. Term Limits. Patient-participants serve for one-year terms. An individual may not serve on the PHPAB for more than three consecutive terms.
- e. Compensation.
 - i. Each PHPAB member will be provided \$400 for each one-year term of service. Payment will be made upon completion of the term.
 - ii. Additional compensation might be provided from time to time, at the discretion of the Co-Chair (described in III.b.i.) if the PHPAB undertakes special projects that require substantial effort above and beyond preparation for meetings and reasonable communication requests.

V. Meetings

- a. Regular meetings are to be held on a quarterly basis (*i.e.*, once every three months or four meetings within a 12-month period). Meetings typically will be two hours in duration and typically will be held in January, April, July, and October.
- b. Special meetings may be convened when necessary to address urgent matters for which PHPAB input or decisions are required prior to the next regular meeting. Special meetings may only be called upon agreement of the faculty facilitator and the chair.
- c. Meetings may be held in-person, by phone, or online. The Co-Chairs will determine the format used for each meeting.

VI. Miscellaneous

- a. These operational guidelines may be amended from time to time.
- b. An application form may be created and distributed publicly to help assist interested individuals who might not otherwise know what to submit to indicate their interest (as described in IV.b.ii)
- c. Invited members for the PHPAB will be given a copy of these operational guidelines and asked to complete an acknowledgment form before beginning a term.