**The Project**

Governance Document

|  |
| --- |
| **Table of Contents** |

**Full Name**…………………………………………………………………………………2

**Flexibility**………………………………………………………………………………….2

**Mission**……………………………………………………………………………….......2

**Purposes**……………………………………………………………………………………2

**The Partnership Team**……………………………………………………………....3

**Membership & Attendance Policies**………………………………………….4

**Meeting Proceedings & Current Decision-Making Strategies**…...6

**Decision Making Strategies: Details & Future Directions**………....8

**Communication**………………………………………………………………………….9

|  |
| --- |
| **Full Name** |

The name of our organization is fully presented as such:

**FULL NAME HERE**

|  |
| --- |
| **Flexibility** |

The necessity for the adoption of a set of governing rules for our growing partnership that are simultaneously comprehensive and flexible is at the forefront of our considerations as we develop this document. Similarly to the occurrences of everyday life, the community-based and ever evolving nature of pragmatic research undertakings oftentimes gives rise to a need for innovation and adaption in the midst of a project. Over the course of Tier I, we have learned a great deal about the nature of patient centered research and the unique considerations that must be made to promote a steadfast and truly productive project. Some partners will be consistent in their commitment; others will not. Some decisions will be obvious, clear cut, and supported by all members of a meeting; others will be points of contention and debate. Some ideas for future comparative effectiveness research will be parsimonious and straightforward; others will be complex and abstract, requiring additional resources and group analysis to support their conceptualization and maturation. These are all examples of vital factors that contribute to a robust, innovative, and organically developing partnership. It is therefore the responsibility of the partnership to work towards forging a governance document with structures in place that anticipate these uncertainties while also capturing our enduring values and our uniting mission to investigate influencing factors of our target population’s targeted issue. In this document we strive to create strategic and adaptive governing rules with thoughtful space for changes, in an attempt to achieve the production of research that is relevant, dynamic, and integrative.

|  |
| --- |
| **Mission** |

Our partnership’s specific mission is to establish, maintain, and robustly develop a thriving collaboration between various engaged patient and stakeholder partners and researchers in order to discover, more fully understand, and eventually further investigate critical factors that contribute to developing preventative measures to positively affect the project’s target area.

|  |
| --- |
| **Purposes** |

The overall purpose of this project is to effectively and progressively take community insights into account during the process of developing a comparative effectiveness research question regarding protective factors for the project’s target area. We seek to consistently engage service providers, family members, and the target population alike in order to create a steadfast and reciprocal partnership so that we may gather many perspectives concerning our target issue. We intend to collectively work towards the development of an enduring cohort that operates fundamentally on trust, respect, and an underlying unified desire for progress in positive outcomes for the target population.

Other identified long-term purposes include but are not limited to:

* The effective dissemination of our project findings to patient and stakeholder partners. We will work towards developing novel ways to communicate information to participants and the public in such a manner that they will be able to understand and engage fully with the project. This component will be integral to developing a pervasive, lasting, and salient effect upon the target population.
* Increased interest in, understanding of and excitement towards the patient centered research process. The partnership feels that this has the potential to enhance current approaches to research and reception of research in the general population. Additionally, advocating for and teaching individuals about patient centered research will ultimately contribute to the creation of a national cohort of researchers and stakeholders who will possess a more dynamic toolset for approaching research than traditional methodologies would supply, ideally resulting in richer data sets and more comprehensive, usable and relevant outcomes.
* The enduring empowerment of patient and stakeholder partners. We aim to provide our partners with ample resources, guidance and experiential opportunities such as attending conferences, organizing Town Hall meetings, and creating their own target population-oriented networking events. These actions are ultimately geared towards the nurturing of a growing sense of empowerment and control within patient and stakeholder partners, as well as effectively increasing and underscoring the vital role that these individuals play in the research process as a whole.
* The development of long-term relationships with local and national organizations and target population-specific groups, and the subsequent strengthening of the existing network of such individuals’ resources available in the geographic area selected, and beyond.
* Ultimately developing a relevant and focused research question that has the potential to give rise to accessible findings that will not only be of interest and use to research and academia, but more importantly to our target population and the community at large.
* The collaborative generation of other comparative effectiveness ideas (distinct from the select idea that the partnership team chooses to adapt into a research question) that we can document and discuss with key stakeholders and the community at large in order to catalyze ideas for directions of other future research which will ultimately progress the positive outcomes for the target population.
* The development of a stakeholder-target population based intervention model for the target focus area, useful in future comparative effectiveness research.

|  |
| --- |
| **The Partnership Team** |

The partnership team will consist of the principal and co-investigators on this project, selected meeting facilitators, and research staff involved in project organization. The partnership team shall meet monthly to discuss project proceedings and plan for future meetings. Should any member be physically absent, they will be brought into the meeting via conference call. In the case of total absence, the detailed meeting minutes taken during each partnership team meeting will be provided to the absent member, and they will be verbally debriefed by an attending member at their earliest convenience. As a whole, the partnership team will serve as the governing body from the project’s primary institution and will carry out the project protocol while adapting the proceedings based upon active patient and stakeholder partner input.

|  |
| --- |
| **Membership & Attendance Policies** |

Patient and stakeholder partners shall be recruited from the community by the partnership team and by members of the partnership itself as it progresses and patient and stakeholder partners expand their networking capabilities. Specifically, the partnership team and meeting facilitators are responsible for following up with patient and stakeholder partners to confirm attendance and minimize attrition.

Patient and stakeholder partners will be divided into three categories: the target population, the target populations’ friends and family members, and service providers for the target population.

Each patient and stakeholder partner category will meet separately in months 3-5. In subsequent months, groups will be comprised of a mixture of members from each group in order to promote a fully collaborative and encompassing discussion process.

**Meeting Categories & Member Descriptions**

Individuals of the Target Population

We strive to include individuals of the target population from all aspects/stages of the target population, regardless of their current position within the target population’s sub classifications. They act as key stakeholders for this partnership and are encouraged to participate actively in dialogues at every meeting. The varying perspectives from the different aspects/stages throughout the meetings have been and continue to be useful in helping us to develop a well-rounded understanding of issues facing all aspects of the target population. This aids us in identifying protective factors for the target focus area while taking into consideration similarities and differences between individuals within the target population, and how these may theoretically influence the effectiveness of different protective factors. We have strived to pursue partnerships with individuals within the target population on local, statewide and national levels.

Service Providers

Our partnership includes a wide variety of different types of service providers for the target population, ranging from example E to example M, and more. Thus far, the majority of our service providers have not been affiliated with a primary institution involved with the target population. Aside from gaining the service-provider perspective and establishing and understanding of how different services may help to protect against the target focus area, these meetings also serve as an environment in which different service providers can meet, engage in lively and relevant dialogue, and network with one another. We consider creating and supporting an environment where connections between different service providers can be established and nurtured from meeting to meeting to be a vital aspect of our project, and a very welcome side-effect of our monthly meetings. The service providers give unique insight about how individuals of the target population navigate and manage the various resources available to them, whether federally provided or otherwise. Although it is not a direct requirement of our project that service providers network with one another, their presence at meetings undoubtedly allows for the creation of a space where they may interact and potentially unify to optimize services and resources.

Friends and Family

The friends and family group consists of individuals who either have family members who are of the target population, or who have friends who are of the target population. They add a unique dimension to our project, giving us the perspective of people who often interact with the target population on a daily basis and in largely non-professional settings. Depending on the relationship between the target population and the individual, there is oftentimes a potential for increased candidness between individuals of the target population and friends/family as opposed to a service provider. In addition, friends and family are often privy to the extended histories of individuals in the target population, and may be more likely to recognize behavioral patterns or tendencies as they interact with the target population on a consistent basis. This is an essential aspect to consider for our project. Additionally, it is not uncommon for friends and family members to serve as support or full caregivers for individuals of the target population. It is of great importance to acknowledge the prevalent issue of caregiver burden and its effects upon friends and family, as well as the reciprocal effects upon relationships between individuals of the target population and caregivers due to this dynamic.

The Partnership Team

Additionally, the partnership team actively participates in meetings and takes part in patient and stakeholder partner engagement. The partnership team will include the PI and co-PI, meeting facilitators, and research staff involved with the project (refer to Partnership Team section for more details).

The Project Advisory Group

**Absences & Cancellation Procedures for Patient and Stakeholder Partners**

Should a patient or stakeholder partner be unable to be physically present at a meeting, they are teleconferenced in via an online video conferencing system to ensure their input is heard and made note of.

Should a patient or stakeholder partner be unable to attend a planned meeting and cannot teleconference in, they are required to tell research staff as soon as possible so that the partnership team may carry out additional recruitment. Should a patient or stakeholder partner miss a meeting unexpectedly, the attrition is documented for logistical and budgetary purposes. They are reminded of the availability of meeting minutes on Canvas so that they can remain engaged with meeting proceedings. Their absence shall not impact potential for future participation in meetings in any way.

**Diversity of Stakeholders**

As we have firmly established in this document, understanding the protective factors for the target focus area has required and will continue to require gathering input from many different groups of individuals. Our project design-- meetings with the groups listed above -- is based heavily upon the notion that multiple viewpoints are crucial for developing a comprehensive comparative effectiveness research question. As such, taking into account the diversity within each of our subgroups is also something that we consider to be a priority. We have thus far included significant numbers of both male and female stakeholders in our partnership. Additionally, we have managed to include patient and stakeholder partners from a span of different generations. As discussed above, we have also tried to include members from various aspects/stages of the target population. In our future meetings, the group recognizes the need to strive to include a greater number of individuals of color in this project, as the experience of minorities within the target population may differ in significant and impactful ways. These differences could have a marked effect on the effectiveness and prevalence of different protective factors for the target focus area within different aspects/stages of the target population. Additionally, the partnership team has identified the need to include viewpoints from the Lesbian, Gay, Bisexual, and Transgender (LGBT) community in addition to the current perspectives we have collected. In an attempt to expand the scope and diversity of our meetings, we are still in the process of contacting several different local and national LGBT groups in order to develop a more inclusive examination of protective factors for the target focus area.

**Compensation for Patient and Stakeholder Partners**

Patient and stakeholder partners are compensated for their participation in meetings. In months 3-5, a $26 dollar gift card was given to all patient and stakeholder partners who attend meetings, as well as a meal. In months 6-8, patient and stakeholder partners received a $5 gift card as well as a meal. Patient and stakeholder partners are compensated for parking costs at meeting venues.

|  |
| --- |
| **Meeting Proceedings & Current Decision-Making Strategies** |

Throughout the various stages of our project, the partnership team will make every effort to keep patient and stakeholder partners actively engaged in and updated with meeting proceedings. Additionally, patient and stakeholder partners will play an active role in determining the guidelines for our decision making processes.

Meetings in Months 3-5

In the initial monthly 90-minute patient and stakeholder partner meetings during months 3-5 of the project, meeting minutes were recorded based upon discussion content and suggestions made by patient and stakeholder partners regarding protective factors for the target focus area. Patient and stakeholder partner meetings were held once monthly for each group listed previously. The content of these minutes continued to play a part in helping partnership team members reference potential protective factors. Additionally, the content of these meeting minutes helped to decide the focus of our Executive Partnership Team (EPT) meetings, aided us in ensuring that we are communicating adequately and efficiently with partners, and will eventually help the partnership in crafting a comparative effectiveness research question, directly according to patient and stakeholder partner input. Thoughts and insights were taken into account and the meeting minutes are available to patient and stakeholder partners via an online platform. Patient and stakeholder partners were made aware of the communicative importance of the minutes and were encouraged to give suggestions for additions, deletions, or other changes to the minutes.

Meetings in Months 6-8

In months 6-8 of the project, and Executive Partnership Team (EPT) was created, drawing from patient and stakeholder partner groups listed above. Patient and stakeholder partners who participated in the bimonthly 90-minute EPT meetings were not strictly required to have attended a meeting in months 3-5. The EPT meetings delved further into issues and ideas discussed in meetings during months 3-5. The EPT identified and addressed problems and questions that developed during the course of discussions, and with the help of the EPT the partnership team will conducted needs and capacity assessments throughout months 6-8, aiding us in addressing factors that we needed to address and bolster in order to strengthen our partnership and move forward. Importantly, the EPT served to prioritize issues and ideas examined in months 3-5. The EPT also actively developed the midpoint report version of our governance document in order make it as comprehensive and versatile as possible. The governance and recruitment documents were distributed at various EPT meetings, were made available on our online platform, and were repeatedly sent out to EPT members in order to ensure that everyone had access to these documents and adequate opportunity to contribute their opinions and insights. We decided upon voting procedures over the course of our EPT meetings (Robert’s Rules of Order; majority rule on final decisions regarding meeting proceedings such as ‘Do we agree on the Tier II Abstract?’—refer to Decision-Making Strategies: Details & Future Directions section for further details). We engaged with the EPT in a variety of ways in order to develop goals regarding moving forward in shaping governing structures and investigating protective factors for the target focus area and developing a relevant comparative effectiveness research question.

Structured EPT activities included but were not limited to:

* Collaborative idea generation via a Liberating Structure exercise: 1-2-4 All. In this approach, we had EPT members individually identify two or three different ideas for the protective factors that they felt were potentially significant **and** currently under-researched. We also asked EPT team members to consider **why** they felt that these interventions were under-researched, not well known, etc. We then asked individuals to pair off, discuss these things in groups of two, then in groups of four. As a group of four they chose three protective factors that they collaboratively felt were most significant. They then presented these factors to all partners in attendance at the EPT meeting.
* Specific discussion of the progression of the Tier system, funding, resources, and the process that goes into developing a comparative effectiveness research question, along with a Q&A session afterwards.
* A PowerPoint presentation which more inclusively explained what comparative effectiveness research is, gave examples of potential topics for CER questions based off of recurring topics from meetings in months 3-5, as well as gave examples of an actual CER question for reference (not based on our topic).
* Outline of the functions of the Advisory Group, its roles and responsibilities, and collaborative brainstorming of ideas for Tier II activities.

Meetings in Month 9

In month 9, an Advisory Group was selected from members of the EPT. Potential members were selected based on demonstrated interest and various qualities such as consistent commitment, innovative spirit, and ability to work well with the group dynamic in a constructive and productive manner. The Partnership Team sent out emails to potential Advisory Group members and then held an initial Advisory Group meeting with all approved members on a date in time. The Advisory Group will work towards various goals identified by the EPT, plan future activities, and be an integral part in the dissemination of project findings to patient and stakeholder partners as well as the community at large. The Advisory Group will operate specifically based off of activities outlined in our Tier II Work Plan (refer to auxiliary Work Plan document for more details).

|  |
| --- |
| **Decision-Making Strategies: Details & Future Directions** |

In months 6-9, of our Tier I partnership we solidified some simple decision making strategies.

**Advisory Group Voting**

* Development of voting procedures to amend our governance document, approve recruitment strategies documents, abstract, and other important deliverables.
	+ All ideas will be discussed freely and in an orderly manner; formal motions for bringing up topics are not necessary.
	+ In the event that there is not a total consensus on an idea or action, formal voting will occur. Majority rules in order for formal decisions to pass; hands will be raised and ayes and nays will be counted.
	+ To table or “lay aside” a discussion to be paused and revived at a subsequent meeting, a second is needed and a majority vote required to table the item in question.
	+ ***As of the end of Tier I***, in the event of a tie, the PI and CO-I would confer and make a decision based on their best judgment on the issue at hand. However, this rule is to be further debated and adapted in Tier II, and a more encompassing and involved mechanism for deciding ties is to be set by the Advisory Group. It should be noted that thus far, we have not happened on to any highly contentious decisions in which a tie has occurred. However, this does not exclude the possibility of a tie in Tier II, particularly with increased Advisory Group meetings, planning, and CER idea debates.
* Rules for Inclusion of Potential Protective Factors into Discussion for CER Ideas/Questions
	+ In the spirit of inclusivity and collaborative efforts, all ideas will be included by default. If there is an idea that is flagged by Advisory Group to be questionable or not of merit, it shall be discussed and voted on to decide whether to be kept or rejected. Majority rules in order for formal decisions to pass; hands will be raised and ayes and nays will be counted.
* Rules of order and speaking during EPT meetings
	+ One person shall speak at a time; however, hand raising is not required to speak. The meeting facilitator or a member of the partnership team will call for order if there is excessive and disrespectful crosstalk.

**Future Decision Making Enhancements**

* In the future, we plan to hold mini-debates during Advisory Group meetings, and discussions centered on specific topics (possibly those identified in literature reviews) and CER ideas. We will also hold comprehensive and orderly discussions regarding planning for networking events and town hall events, presentation details, and the selection of representatives for attendance to conferences. Advisory Group Voting will occur to define best proceedings if there are identified points of contention. As mentioned, we will work with the Advisory Group to further develop our methods for deciding on a tie in contentious situations.

|  |
| --- |
| **Communication** |

Communication Strategies between Members of the Partnership

Successful and open communication with patient and stakeholder partners has been and will continue be an integral part of the project. In order to create a highly communicative environment conducive to successful recruitment, discussion, and an active flow of knowledge and ideas, we have devised several key strategies operating on different platforms.

**Email Group**

This is the official email address for the project. It will be used to contact future participants, current participants, and past participants at the end of the project (for dissemination purposes). Primary functions of this platform include but are not limited to:

* Official recruitment confirmations
* Updates on meeting times, places, other small details
* General patient and stakeholder partner correspondence regarding the project, including questions and concerns.

**Social Media Group**

This is a closed group on a well-known, widely used social media platform. Patient and stakeholder partners from each group are invited via email to this group after supplying their email addresses at each meeting, and are encouraged to join. If they choose to join, the group may serve as an additional source of communication and connection for patient and stakeholder partners. Primary functions of this platform include but are not limited to:

* General sense of support and community for patient and stakeholder partners
* Place where questions or concerns may also be brought up
* Platform on which recruitment discussions may be initiated
* Place where meeting reminders and reminders about the posting of meetings minutes will be added so that patient and stakeholder partners have as much access as possible to project development

**Online Page**

This is a social media site in which all patient and stakeholder partners are enrolled, and where project documents can be officially and shared in order to fully immerse patient and stakeholder partners in the project and the details of our meeting proceedings, logistics, and governance. Primary functions of this platform include but are not limited to:

* Posting of meeting minutes from each stakeholder meeting
* Posting of documents regarding the goals, outline, and development of the project
* Posting of interesting minutes taken by research staff during PCORI Webinars
* Posting of useful target population resources
* Posting of governance documents
* Posting of recruitment strategies

Communication Strategies regarding Dissemination of Information to the Community At Large

**In-Person Communication**

* Advisory Group-organized networking events with key stakeholders and potential community partners to discuss CER ideas
* Advisory Group-organized Town Hall meeting to promote protective factors, discuss and receive feedback on specific CER ideas, discuss project progress, networking ideas, and more
* Verbal, face to face communication about CER ideas and project progress and mission to other researchers, service providers, patients, and friends and family members of the target population at both local and national conferences
* Verbal, face to face communication about CER ideas and project progress and mission to other researchers, service providers, patients, and friends and family members of the target population at local and national target population-oriented events, such as target population support organization fundraisers