



Overview and Goal: The Massachusetts Patient and Community Review Board (Board) provides a thoughtful space for community members to share their insights and experience with health care researchers and programs developers as they begin to design new initiatives. Organized by the [Massachusetts Coalition for Serious Illness Care](#) in partnership with the [Patient Advocate Foundation](#) (PAF), the goal of the Board is to ensure that our health care systems are investing in research and programs that best serve the needs of communities across Massachusetts. This is especially important for communities that are underinvested in and underrepresented – those often with the highest needs, yet least likely to have their voices heard. The Board will focus on reviewing research and programs about people with complex or chronic illnesses and conditions. Board members will bring their own lived experience as patients or caregivers as well as the broader perspectives of the communities they are closest to, either in their personal lives or because of where they live and work.

So how will this work? In partnership with collaborators at the [Patient Insight Institute](#) (PII), a program of PAF, we will recruit 12-15 people from Massachusetts to sit on the Board for renewable, one-year terms. Interested members will submit an application outlining their interest, experience, and the perspectives they hope to bring to discussions. We will select Board members with an eye towards diversity of thought and experience, with a goal of over-representing people from underinvested communities. Board members will be paid an honorarium of \$150 per meeting for their service and given appropriate training and education to prepare them to fully participate in conversations about research and program design. The Board will provide guidance at project conception and planning stages before researchers seek funding or Institutional Review Board approval.

The design of the Massachusetts Patient and Community Review Board, inspired by the [PII's Experts by Experience Board](#) and [Harvard Catalyst Community Coalition for Equity in Research](#), will help build and strengthen relationships and connection between Massachusetts' health care systems and communities while building longstanding community capacity to engage in health care research and program development.

For Patients and Community Members:

Why would you want to join the board? Health care researchers and organizations want to help improve the quality of health care for patients. But they often don't have good ways to connect with the patients, families, community leaders, and advocates who know the most about what ideas and programs might work best. This Board is a chance to share your insights and expertise about the questions that need answering and the programs that should be created that get to heart of the issues and challenges you and your community are facing. It's a unique opportunity to have your voice heard and help improve care for everyone.

Board Member Expectations:

- Commit to a one-year term with the opportunity to serve for another year
- Come prepared for each meeting ready to share your personal experiences related to the research or program idea being presented:
 - Share insights from your own experiences as a patient or caregiver as well as any broader experiences from the communities you are closest to.
 - In preparing, ask yourself: is this researcher asking the right questions about the issue? How would the proposed research or program impact you or your community? Is this something you or your community would want to be a part of? Is it designed in a way that would allow easy access, participation, and engagement? Is this research touching on the most important part of the issue or problem being studied or worked on?
- Regularly attend Board meetings and educational sessions. All new Board members are expected to attend an orientation to learn an overview of health care research and quality improvement work.
- Board meetings will be held approximately 8-10 times per year and will include a mix of educational elements and presentations from researchers and program developers on their ideas.
- As thanks for your service, Board members will be given an honorarium of \$150 for each meeting, which was calculated using the National Health Council's [fair market calculator](#). We anticipate that total time for each meeting will be approximately three hours; regular Board meetings will be 90 minutes long and may require up to 90 minutes of preparation and reading.

For Researchers/Program Leaders:

Why would you want to work with the Board? Engaging with the community makes research and programs better. We know that community voice is critical to ensuring that health care research initiatives and programs truly meet the needs and get to the real heart of the issues and challenges facing different communities. But it's hard to find the right people with the right perspectives at the right time to provide this critical insight in the development process.

This Board makes it easier. Because this is a standing Board, meeting approximately every six weeks, there is minimal lead time – we're ready when you are. We will select Board members to ensure a wealth of different experiences and viewpoints, including patients, caregivers, community leaders, and advocates. We'll train them to have sufficient knowledge of clinical research and quality improvement programs to offer high-value insight. Over time, the board will help build long-term relationships and community capacity to engage in these discussions.

Researcher/Program Leader Expectations:

- Bring to the Board research projects or programs that are early enough in their design and concept phase to allow incorporation of meaningful feedback; this should be before applications for funding and/or Institutional Review Board submissions, after which more substantive changes are often harder to implement
- Bring projects or programs that focus on patients with complex and/or chronic health issues
- Invest time in preparing with the Board's expert facilitators the materials and presentation to the Board
- Be prepared to come back to the board with updates on how their feedback influenced your proposal/program, either at subsequent meetings or via other forms of communication
- Note that community board members **are not expected** to help with recruitment or patient engagement, but they may offer to share information with their networks, if it feels appropriate