

DRAFT Charter for a Patient Advisory Board

This charter is designed for open communication with all potential Patient Advisory Board members inside and outside your organization and any other party interested in the purpose of the Patient Advisory Board and the nature of the attendees. Please note that Transparency Codes apply.

We strongly recommend to use this only as a proposal for clarifying your own thinking first and then ask all other involved stakeholders (patient experts, Key Opinion Leaders, others) to comment and add as appropriate. You may even start with an open discussion before drafting with some of the potential advisors you know you want to have on the board. The final charter should be the reflection of the major points agreed upon between the collaborators about why to collaborate on what and how to do that.

Purpose / Mission and Objectives

The “*insert Name of the Board*” shall contribute to (*specify*)...

- *Describe what your company is currently doing, why this requires patient advice and what you hope to achieve from it.*
- *Describe the specific objectives the Board should strive to to achieve in as much detail as possible (“to learn / get insight / discuss...”). Try to put yourself into the shoes of the potential patient advisory board member reading this who shall make a judgement call on whether to join or not based on this charter.*
- *Input from (already) appointed members of the board, both inside and outside your organization, is valuable to improve the charter.*

Members and Responsibilities

The “*insert Name of the Board*” consists of (*specify*)...

Describe the desired profile of the external and internal board members and their expected roles:

- *Who should chair the Board? Is an independent, external chair required? And what are this person’s responsibilities? e.g. The Board will be chaired by “insert name and function”. The Chairperson is responsible for preparation of the meeting including draft agenda for input by the Board, final agenda, moderation of the Meeting itself, Meeting Minutes and any follow-up items.*

- Describe the Patient Advisors on the board and their roles, names and backgrounds/functions: e.g. “There will be 5 Patient Advisors on the board:
 - a Patient Advocate on behalf of Patient Organization A
 - a Patient Advocate on behalf of Patient Organization B
 - 2 patients diagnosed with (specify indication), who have experience with (specify, e.g. specific treatment, a specific patient support program or more general “clinical development in disease X”)
 - an experienced patient nurse / a social worker / a caretaker
- Describe the employees of your organization who should be on the board and their expected roles, names and functions: e.g. “There will be 5 Company Representatives on the board:
 - The Head of Clinical Development
 - The International Project Lead
 - The Head of Market Access
 - etc.
- an experienced patient nurse / a social worker / a caretaker
- Describe any other external Advisors (e.g. physicians) you may want to have on your board and their expected roles

Organization and Logistics of the Patient Advisory Board

The “insert Name of the Board” will meet (specify)...

- Describe in detail the frequency of meetings, whether they are in person or via phone/web conference, the duration and location
- Clarify whether confidentiality agreements are in place and provide for the board members’ freedom to communicate about the confidential information between each other. e.g. “The board meetings will be subject to confidentiality as agreed individually in written form between the company and the board members.”
- Make sure provisions are taken to ensure all Board members “speak the same language”, hereby taking into account not everyone may be fluent in English and avoiding misinterpretations. Also, local boards can be in a different language: e.g. “All board materials and the board meetings will be in English language. Where needed translation of materials and during meetings will be provided for.”
- Make sure all participants agree on time needed for preparation, e.g.: “Board members shall prepare for the board meetings based on the material provided by the Chair, which shall not exceed more than (...specify estimated time...) per board session.”
- Provide for detailed loops before, during and after each session regarding possibly required adaptations.

Source: This charter has been developed by admedicum® Business for Patients GmbH